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**Improving the experiences of palliative care for older people, their carers and staff in the Emergency Department using Experience-based Co-design**

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King's College London

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**Florence Nightingale Faculty of Nursing and Midwifery**

**Improving the experiences of palliative care for older  
people, their carers and staff in the Emergency  
Department using Experience-based Co-design**

Rebecca Jane Blackwell

Thesis submitted for the degree of

Doctor of Philosophy

University of London

July 2015

## **DECLARATION**

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Signed.....

Date.....

# ABSTRACT

## Background

The Emergency Department (ED) is often viewed as an inappropriate environment for terminally ill older patients; however, palliative admissions to the ED continue to occur. Despite an increased focus on end of life and palliative care services, the role of the ED has generally been neglected in the UK.

## Aim and Methodology

This study used the participatory action research methodology, Experience-based Co-design to identify concerns and solutions to improve experiences of palliative care provision in the ED for older patients (65+), their carers and staff at Guy's and St Thomas' Hospital NHS Foundation Trust ED.

## Methods

Experiential narrative data were gathered using audio and filmed interviews, and analysed using a thematic framework to identify the main challenges. Findings were validated by the staff and patient/carers groups, who selected four improvements priorities (IP) each (eight in total). Findings, in the format of a patient/carers film and a staff presentation were shared at a co-design event which enabled participants to collaboratively select shared IPs and began to redesign applicable elements of the service.

The study was enhanced by findings from a data collection field trip to a geriatric-only ED at Mount Sinai Hospital in New York.

Using interviews and observation additional background contextual data on palliative care coding and ED impact on the patient journey were identified.

## Findings

The four staff IPs were: 'helping them [patients and carers] find their way', 'being informed and informing them [patients and carers]', 'seeing the person in the patient', and 'expectations of the care we can give'. Patient and carer IPs were similar: 'finding our way', 'knowing what's happening', 'seeing the person in the patient', and 'expectations of care'. The co-design event explored these issues and the group began to develop plans to improve them. Immediate strategies aimed to: improve self-management and ownership, develop ED-based palliative care pathways and staff training, create dedicated palliative care space in the ED, improve IT and databases, improve patient experience, and share the learning of the study.

## Impact

Early study impact includes palliative care referral improvements, introducing routine ED visits by the palliative care team, development on palliative care pathway processes in the ED, development of mandatory palliative care training in the ED which includes the patient/carers film. Based on feedback from the co-design event, the film was expanded to include the staff experience as well.

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## **ABBREVIATIONS**

A&E – Accident and Emergency

AR – Action Research

BDP – Broad Design Principle

CARE – Care And Respect for the Elderly

COPD – Chronic Obstructive Pulmonary Disease

DNR/DNAR – Do Not (Attempt) Resuscitation

DP – Design Principle

EBCD – Experience-based Co-design

ED – Emergency Department

GEDI WISE – Geriatric Emergency Department Innovations in care through Workforce Informatics and Structural Enhancements

GSTT – Guy's and St Thomas' NHS Foundation Trust

HOT – Hospital Outpatient Treatment

LCP – Liverpool Care Pathway

PAR – Participatory Action Research

PDN – Practice Development Nurse

PTWR – Post Take Ward Rounds



## PROLOGUE

‘A quality PhD tells a compelling story’ (Winter et al., 2000). Consideration of what such an evocative statement meant for this thesis led to a critical review of the original draft, which had followed a standard chapter presentation of the stages of a doctoral study. Social science academics argue against a quantitative formulaic approach (Introduction, Methods, Results, Discussion) in an Action Research (AR) study. Instead, they recommend a chronological narrative that allows the story of the project to unfold in the writing as it did in practice, providing an honest and rigorous retelling (Zuber-Skerritt and Perry, 2002, Fisher and Phelps, 2006, Zuber-Skerritt and Fletcher, 2007). I have therefore adopted this narrative approach, and, although the traditional lynchpins remain (literature review, methodology, findings and discussion), they are given as part of the story, used to support and enhance the thesis, rather than as a structural framework. The former method would, ultimately, have inhibited the telling of the AR story, by presenting a project that looks quite different to the one actually experienced by the researcher and participants.

By accepting the social science ontology, and choosing to write this thesis as a narrative, I rejected the positivist perspective of how experiences and realities are understood (Fischer, 1998). This includes the concept of a researcher being so objective that they do not affect their work or find themselves affected by it, but instead perform as a dispassionate outsider; a stance widely dismissed as unrealistic by AR academics (Zuber-Skerritt and Perry, 2002, Fisher and Phelps, 2006). Instead, my role as an AR researcher implies that I needed to be aware of, and reflect upon, my influence and impact, as I actively engaged with palliative patients, their carers and Emergency Department (ED) healthcare staff, within the systems of the ED and palliative care pathways (Zuber-Skerritt and Perry, 2002). It was agreed at the First Symposium on Action Research in 1989 that a quality AR project must incorporate this critical and self-critical reflection (Zuber-Skerritt and Fletcher, 2007), and the use of first and second person voices to weave a common thread through different aspects of a project, seemed a clear and interesting approach. This is not an unprecedented format and the use of multiple voices to critically reflect on the processes and conduct of a study has been used to present AR doctoral research before (Fisher and Phelps, 2006).

Within my thesis there are two clear stories and therefore two clear voices. The first is that of the project itself, presented as a third person narrative telling the story of this AR study that

uses the methodology Experience-based Co-design (EBCD) framed within a changing medical-social context and buffeted by many challenges. The second voice tells the story of my role as the researcher leading this study, told as a critical reflection in a first person narrative at the conclusion of each chapter. The process of critical reflection drew on approaches to reflective practice; Johns and Gibbs (Gibbs, 1998, Johns, 2013), to offer a structure and format, as well as guidance and prompting questions throughout the process. Gibbs' Reflective Cycle (also known as Gibb's Reflective Model) provides a broad structural framework for iterative reflection (Gibbs, 1998). The reflector follows six stages, drawing them through description, feelings, evaluation, analysis, conclusions and on to the development of an action plan. This reflexive cycle allows for the critical reflection inherent in AR, but also leads the reflector back to action. The works of Johns (Johns, 2013) suggests that reflective practice is a multi-faceted approach to 'being', encompassing among other elements; mindfulness without judgement; reflexivity to gain insight into what has previously occurred and practical wisdom. Johns' work provided the theoretical underpinning for ensuring that the process of critical reflection was not just something I would be *doing* throughout the study, but rather the way in which I was *being* and conducting myself; developing my role as a researcher within a reflexive ontology. The epilogue concluding this thesis offers a critical review of the reflective practice I undertook during this study that was grounded within these approaches. Expert Action Researchers advocate making explicit one's stance as the external researcher, early on in the work '*...as action research (and, indeed, any research) is formed and influenced by the researcher's values, attitudes and beliefs, I saw it as important to articulate these...*' (Fisher and Phelps, 2006, p. 151). Therefore, presenting the format of the thesis as a narrative is not the only function of this prologue. It also serves to present the driving force and ethos that underpin my entire PhD thesis, before introducing the purpose of this thesis with its aims.

As stated, the use of different voices can serve as a mechanism for presenting the narrative of the study and for critically reflecting on the inevitable influence of the researcher. (Fisher and Phelps, 2006). The rumination for this study began in 2007, while I worked at a South London hospice as a palliative care nurse. Distressing ED interactions were shared with me by patients and families in my nursing care, and ED colleagues I worked alongside. Such negative experiences were sadly frequent, but at that time there was very little work or recognition of the palliative care patient group, who are out of place in the traditional ED system, and the struggles of ED staff to provide a form of care counterintuitive to their usual

practice. My concern for these vulnerable groups (palliative care patients, their families and ED staff) led me out of clinical practice and into research, in order to explore and improve their shared experiences. Within the thesis I discuss my changing understanding and perceptions of patient, carer and staff needs, as I learned to silence my own expectations and assumptions about their lived experiences. This reflection and learning occurred within the context of an emotive topic, and one that I care deeply about. Therefore while the thesis acknowledges my own emotional and personal connection to the co-collaborators and the outcome of this work, the selected methodology manages these factors through the iterative involvement and engagement with participants, as well as on-going critical self-reflection.

To summarise, as the researcher I am an external and effecting facilitator of the project, influenced by, and influencing its development but separate from the ‘main players’: the patients, carers and staff. The impact of the study on these co-collaborators was quite different from the impact it had on me; the following thesis has sought to reflect these two parallel, and occasionally, overlapping stories through a dual-voiced narrative.

### **Study aim and purpose**

The aim of this thesis was to explore how to improve experiences of palliative care for older palliative patients, their carers and staff in the Emergency Department (ED) using Experience Based Co-Design (EBCD).

As the following chapters demonstrate, the ED is often viewed as an inappropriate environment for palliative and terminally ill patients. Despite this, palliative admissions to the ED continue to occur for a variety of reasons including relative distress, lack of community support, and disease progression. In recent years there has been increasing focus on end of life and palliative care, particularly for older people. However, there is still no definitive answer as to how to care for palliative patients in the ED, although there are emerging protocols and suggested methods of department reorganisation, much of which has been done overseas with little from the UK.

This study sought to identify the main concerns for patients, their carers and ED staff in the provision of ED-based palliative care at Guys and St Thomas’ NHS Foundation Trust (GSTT) using the participatory action research methodology, EBCD. From this point forward the research site will be referred to as ‘St Thomas’ ED’, and the term ‘carers’ refers to informal, unpaid family or friends who accompany and care for the palliative patients. The methodology used audio and filmed interviews to gather experiential data, thematic

framework analysis and participant validation to identify main concerns, and a co-design event where participants worked together to begin to redesign those elements of the service causing the greatest concern. To further enhance and support this work, a travel scholarship was awarded by the Florence Nightingale Foundation which enabled a month long data collection field trip to a geriatric-only ED at Mount Sinai Hospital in New York. This department is staffed by clinicians who are developing expert care for older people in the ED, many of whom have palliative needs. Broad design principles for redeveloping EDs to cater for the needs of this population were extrapolated from the data and fed back to the research site in the UK to further develop, support and inspire the final outcomes of this EBCD process.

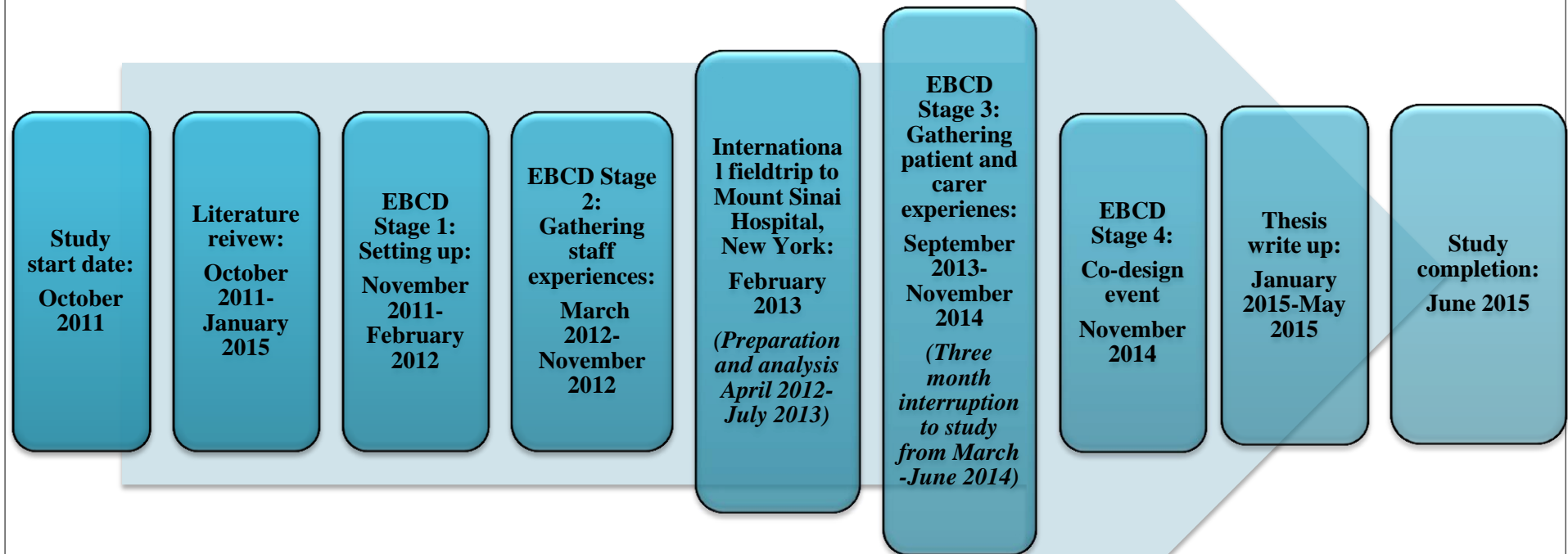
### **Structure of the thesis**

In the following chapters the narrative is led through the research to meet the aim of improving experiences of palliative care delivery for older patients, their carers and staff in the ED. Starting with Chapter One ‘Setting the Scene’ the narrative explores the background and context for the study, revealing the need for this thesis. Chapter Two ‘Informing The Story’ presents the literature available at the start of the work that informed the conduct of the research. In Chapter Three ‘Preparing To Find The Story’ a detailed examination of the methodological approach used in the thesis is presented, referring to the epistemological and ontological perspectives. Chapters Four to Seven contain the various stages of the research process, moving through ‘The Staff Story’, ‘The New York Story’, ‘The Patient And Carer Story’ to the final part of the research process ‘The Shared Story’, in which patients, carers and staff work together to redesign the delivery of palliative care in the ED. Chapter Eight ‘The Influence And Consequences Of The Study’ reflects on the outcomes and effect of the research project before an epilogue concludes this thesis. The DVD which is an integral part of this research should be viewed following Chapter Seven, as its final iteration was a direct result of the work conducted collaboratively by the patients, carers and staff involved in this thesis.

### **Study timeline**

This study was conducted over four years from October 2011 to the completion of the EBCD research in December 2014. The timeline below (Figure 1) serves as a guide to the reader and is referenced throughout this document.

**Figure 1: Timeline of study from 2011-2015**





# **CHAPTER ONE: SETTING THE SCENE**

## **1.1 Introduction**

Chapter One sets the scene for the research which explores how to improve the experiences of palliative care delivery in the Emergency Department (ED) for older patients, their carers and staff. Palliative care, the ED and older patients are three separate but interwoven threads which run through the thesis. In recent years aspects of all three of these threads have developed and at the present time, in 2015, claims of ‘crisis’ have been attributed to each (Ross, 2013, Williams, 2013, Blunt et al., 2015).

## **1.2 Chapter overview**

This chapter uses published literature to present the background and context of this thesis, exploring the histories of palliative and emergency care. It describes the way in which they have become woven together in caring for an ageing population inspired the research and influenced its development. Within the story of the research, literary data refers to the documented telling of the social perspectives, opinions and evidence generated by public, academic, medical and government bodies. This literary data played a role of collaborator, as significant as the staff, patients and carers. It influenced the process, management and findings in a marked way that is discussed and reflected upon as it happened chronologically throughout the study. As this chapter progresses, the study population and purpose of the study are introduced. The chapter concludes with a self-critical reflection on the personal impact of undertaking research during a critical time within the NHS for all three threads of the study.

## **1.3 Terminology and definitions**

All three threads of the thesis: palliative care, emergency care and care of older people are complex issues with challenges pertaining to their definitions. Before setting the scene and providing the background context of the thesis, an explanation of the definitions and challenges is provided. It should be noted that detail pertaining to older people has been drawn from different source data that use different parameters for the classification of old age.

Any research into palliative care needs to acknowledge the challenges inherent in its definition and application, as well as clarifying the definition used within that research

(Goodman et al., 2012). Personal challenges in selecting the definition used within the research are discussed in the critical reflection.

Coming from the Latin, ‘palliate’ literally means ‘to cloak’. A broad explanation is that it refers to the amelioration or masking of symptoms caused by terminal disease. This is achieved through a multidisciplinary bio-psychosocial-spiritual approach to care, such as medication, counselling, and various complimentary therapies, for instance art and massage (National Council for Palliative Care, 2015).

This thesis uses the terms ‘palliative care’, ‘terminal care’ and ‘end of life care’. The definitions are drawn from four sources. First, the definition of palliative care which is widely accepted and recognised is that provided by the WHO (World Health Organisation, 2011). Second, the definition of terminal care comes from a recent report published by the National Institute for Health Research (NIHR) which explores end of life care research (Goodman et al., 2012). Thirdly, end of life care is defined by a Canadian publication outlining end of life guidelines for older people as the final year of life (Ross et al., 2000). This definition is also used by the NIHR report, which provided consistency in use and application. The fourth and final source gave clinical guidance as to those conditions that can be constituted as ‘palliative’. This source is a research publication exploring end of life care needs in older people in the ED, undertaken at St Thomas’ ED (Beynon et al., 2011). The definition forms the basis for the inclusion criteria for palliative care patients involved in this study. The definitions used are therefore:

Palliative care:

*“...palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual...”*  
(World Health Organisation, 2011)

Terminal care:

*‘Terminal care is usually associated with the last few days and hours of life, and based on the knowledge that the individual is dying.’* (Goodman et al., 2012, p.3)

End of life care:

*‘End-of-life care for seniors requires an active, compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life-threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement.’* (Ross et al., 2000, p.9)

Clinical definition:

*‘Broad: cancer or chronic obstructive pulmonary disease (COPD) or heart failure or renal failure or liver failure or neurological disease (multiple sclerosis, Parkinson’s, dementia, motor neuron disease) or >2 co-morbidities on Charlson Index*

*Narrow: cancer or COPD or heart failure or renal failure or liver failure or neurological disease (multiple sclerosis, Parkinson’s, dementia, motor neuron disease) or >2 co-morbidities on Charlson Index AND symptoms (pain, breathlessness, nausea, weight loss, confusion, anxiety) and/or complex social needs.’*

(Beynon et al., 2011, p.492)

The medical specialty ‘palliative care’ is often misunderstood by the public and healthcare practitioners. One of the main reasons for widespread ambiguity is due to the origins of palliative care as a philosophical ideal rather than as management of a clear-cut pathology, as is typically the case in medicine (Fallon and Smyth, 2008). The vast and complex nature of palliation has led to the creation of several different definitions which can be vague and lengthy, discussing the holistic philosophy rather than any cogent clinical activities (World Health Organisation, 2011, National Council for Palliative Care, 2015). In addition, as the provision of palliative care has evolved over the past five decades descriptive terms and their meanings have evolved with it (Mathew et al., 2003). Definition is important as it helps to provide guidance about who is to do what, with, and for the patient and their family. The World Health Organisation’s (WHO) definition is one of the most commonly cited as it develops palliative care into an approach that cares for the whole person rather than a response to a specific disease (Hui et al., 2012).

Despite the widespread use of this definition it contains complications for clinicians and patients as there is no direction as to the manner of initiating or applying palliative care (Smith et al., 2009). To add to the confusion there is also a lack of standardisation in the use

of palliative terminology in practice and literature (Hui et al., 2012). Terms such as ‘end of life care’ ‘terminal care’ and ‘supportive care’ are often used but applied interchangeably, and rarely with a clear definition, for example when and how in the disease trajectory these terms apply (Hui et al., 2012). Such disparities can have negative implications clinically, administratively and academically, whereby a lack of shared understanding of terms can complicate communication and perceptions of care processes for patients and clinicians alike (Fallon and Smyth, 2008, Marco et al., 2009, Pietrzynska et al., 2009, Muller-Busch, 2011, Hui et al., 2012).

A significant area of debate is in the relationship between palliative care and end of life care. In 2011 the WHO updated their definition, incorporating end of life care into palliative care as a specific end stage (World Health Organisation, 2011). However, quite when and how this phase occurs in the palliative process is also not universally agreed upon. This is further complicated by the fact that each person is an individual with unique needs and experiences, which makes it impossible and inappropriate to be prescriptive about many of these issues (Goodman et al., 2012, Williams, 2013).

In the midst of this debate are controversies about the roles of different practitioners in the actual provision of palliative care. Increasingly policies and guidelines are directing palliative care to be a more central activity for general practitioners (General Medical Council, 2010, Leadership Alliance for the Care of Dying People, 2014a). Many palliative care specialists claim that palliative care is for all staff to provide to any patient in need (Gardiner et al., 2011). However, literature indicates that healthcare practitioners including, most pertinently for this thesis, ED nurses and doctors, often feel ill-equipped to meet the needs of their palliative patients, and are uncertain or in disagreement about their role in the provision of palliative care within their unique clinical settings (Rodriguez et al., 2007, Beckstrand et al., 2008, Smith et al., 2009, Gardiner et al., 2011, Grudzen et al., 2011b, Shearer et al., 2014). This is explored in more depth later in the thesis.

The final area to be recognised within a discussion of palliative care definitions as it relates to this study is that of geriatric palliative care. Some practitioners and researchers have raised the need for, and explored the development of, palliative care for older people (Winzelberg, 2005, Kapo, 2007, Pautex et al., 2010, Unroe and Meier, 2013). This is important, for despite considerable overlap between the principles and practice in palliative and geriatric medicine (Goldsmith, 2010) there are specific age-related challenges. These include medication

interactions and conducting comprehensive geriatric assessments in the limited timeframe of the ED (Pautex et al., 2010).

Moving the narrative on to the second thread, Emergency Medicine and the ED, it is defined as:

*“A field of practice based on the knowledge and skills required for the prevention, diagnosis and management of acute and urgent aspects of illness and injury affecting patients of all age groups with a full spectrum of undifferentiated physical and behavioural disorders. It further encompasses an understanding of the development of pre-hospital and in-hospital emergency medical systems and the skills necessary for this development.”*

(The College of Emergency Medicine, 2010)

Within the UK, the formal and recognised location for the provision of emergency medicine is the ‘Accident and Emergency Department’ (A&E) (Department of Health, 2013). However, as this thesis has international application, to remain consistent with the transnational definition used by the specialty, A&E is replaced with the term ‘Emergency Department’ (ED) (The College of Emergency Medicine, 2011, Department of Health, 2013). The only time A&E is used in this thesis is within formal research documents provided to those without knowledge of the specialty, such as the patients and carer groups.

The third and final thread of the study is older people. Defining the exact age that a person is classified as ‘old’ is a challenging issue due to variations in life expectancy globally, individual health status, and most recently, demographic changes in the older population which are addressed later in this chapter (World Health Organisation, 2015). It is generally accepted in developed countries that ‘old age’ is classified as starting at 65 years of age, based on the usual age of retirement (World Health Organisation, 2015). This can vary with some literature citing the descriptor ‘older’ as starting at age 75 (Beynon et al., 2011). In accordance with the majority of pertinent literature exploring old age starting at age 65 (Grudzen et al., 2010), within this thesis ‘older people’ will refer to those aged 65 and above.

## **1.4 The development of palliative and emergency care**

The development of palliative and emergency care, along with the growth of the older population and how they interact and use these healthcare services are discussed within three time frames that hold significance to this thesis:

*Time frame 1: 1960-2007* – the emergence of palliative and emergency care in the UK as specialities.

*Time frame 2: 2008-2012* – seminal reports in 2008 recognise demographic changes and influence palliative care and care of the dying in the UK. Omission of the ED in these plans inspired the work of this thesis.

*Time frame 3: 2013-2015* – removal of the Liverpool Care Pathway (LCP) a national end of life care guideline in the UK, along with claims that EDs are in crisis. Both impact on care of older people.

The developments in the time frames affected the conduct and conclusion of this study as it stood within an uncertain social and medical period. Chapter Eight reflects on the impact this had for the study.

#### **1.4.1 Time frame 1: 1960s–2007**

##### ***The emergence of palliative care***

Care of the dying has been part of medical and charitable work for centuries (Clark, 2010), but it was in the UK in the 1960s and 70s that palliative care was recognised and developed. First coined in the 1890s, the term ‘palliative care’ was used to describe the care given to people with incurable cancer. This work was led by Dame Cicely Saunders as part of the hospice movement (Hockley et al., 2013a). The focus was the holistic care of the person and their family, not simply the condition they had. The hospice movement took the development of care of the dying, particularly in regards to pain management, out of the National Health Service (NHS). The intention was to develop a model of end of life care that could be transferred back into NHS (Fallon and Smyth, 2008). An international network developed out of the hospice movement and palliative care was adapted and applied across many parts of the world including North America, Europe, India and Sri Lanka (Clark, 2010). Globally palliative care is still developing, although the actual presentation varies according to different cultures and contexts (Hockley et al., 2013a).

Part of the application to the NHS included hospital support teams and palliative care teams, first implemented in the UK in the 1970s. However, it was not until 1987 that palliative medicine was officially recognised and incorporated as a subspecialty of medicine in UK (Fallon and Smyth, 2008). In the early 1990s, other specialities began to question why better care provision and services were given to oncology patients, and explored implementing the principles into their own fields of work (Cameron-Taylor, 2012). This led to development of

palliative care services, such as the first chair of palliative medicine in Europe and the review of the WHO definition of palliative care to reflect earlier integration of spiritual and psychological support in the disease progression (Fallon and Smyth, 2008). Part of the transfer of the successful model of care from the hospice to the hospital was the development of the Liverpool Care Pathway (LCP) in the late 1990s.

The LCP was developed by the Royal Liverpool University Hospital and the Marie Curie Hospice as a framework accessible to multidisciplinary teams caring for people in the final 72 hours of life. The document was not directive as to the care required by the individual but instead offered a series of prompts for the clinical team to identify those who are dying, and to help guide holistic care for the dying person and their family (Broadbent, 2013). Over the following years the LCP was adapted for use across various clinical and community settings, including the ED (Mirando et al., 2005, Duffy and Woodland, 2006, Shipman et al., 2008, Paterson et al., 2009). Of the many policies and guidelines on palliative care provision published in recent years, the development and later removal of the LCP (see time frame 2013-2015) had the greatest impact for this thesis and its staff and patient population. The narrative explores the reasons for this later in this chapter and in Chapters Four and Nine.

### ***Development of the ED***

As with palliation and care of the dying, emergency care has existed for centuries, for example on battle fields or in response to traumatic accidents (Sakr and Wardrope, 2000). It was formally known as ‘casualty’ due to the nature of trauma and orthopaedic accidents it catered for (Sakr and Wardrope, 2000). It developed as a specialty in the 1960s and 70s, becoming known as accident and emergency (A&E) care based on the inclusion of medical emergencies (Sakr and Wardrope, 2000, The College of Emergency Medicine, 2010). In 2004 the name of the specialty was formally changed from A&E to emergency medicine to be consistent with the international definition (The College of Emergency Medicine, 2011). This was important as models of emergency care differ around the world and a shared definition among those with the same model alleviates confusion (Sakr and Wardrope, 2000).

The term ‘Emergency Department’ (ED) replaced A&E in 2004, and is now the official term used in the UK by those working with the specialty. It refers to a department that provides fast action treatment for acute conditions as well as for traumatic injury (The College of Emergency Medicine, 2010). Despite the formal name change by the College of Emergency Medicine and the intention of gradually phasing out and replacing ‘A&E’ with ‘ED’ (The

College of Emergency Medicine, 2011), the Department of Health in the UK continues to use the term A&E as official terminology (Department of Health, 2013). As stated, this is also the term most commonly used and recognised by patients and carers in the UK.

Despite the wide remit of care and complexities that ED clinicians must respond to, recent policies for the ED often focus on swift ‘through-flow’ of patients (Department of Health, 2004, Lamba and Mosenthal, 2010). Delays in the ED impact on all other aspects of the health system and the new target was designed in response to long ED waits exceeding twelve hours, with patients lining the corridors and sometimes dying there (Department of Health, 2001, Blunt et al., 2015). In response to this the ‘four hour target’ policy was introduced which has strong implications for the care of patients and carers (Department of Health, 2000). The target stated that the maximum length of ED stay for 98% of patients was to be no longer than four hours, with financial implications for the hospital if this target was not met. While this improved the through-flow of patients, research into the impact of the target demonstrated mixed results. Many patients, particularly older people, were found to be hastily discharged from the ED within the final twenty minutes of their four hour stay (Mason et al., 2012). Although this rule was reduced to 95% in 2010 due to an increase in patients waiting over four hours in the ED (The Nuffield Trust, 2015), this policy is a continual source of controversy that is explored during this thesis as it applies to the research, particularly in Chapter Four where staff discuss their experiences of providing palliative care in the ED.

### ***Introduction to the older and palliative patient in the ED***

Due to the severity of the accidents experienced by some of the people who use the ED, ED practitioners witness and care for people who die or are dying (Bailey et al., 2011b). However, increasingly ED staff also witness and provide care for people, predominantly older people, who are dying from terminal and long term conditions (Eby, 2008, Bailey et al., 2011b, Buck and Fahlberg, 2014). These are often more complex to plan and provide medical support for. There have been developments in recent years in the function of the ED, discussed later in the chapter, but finding ways to implement the holistic principles of palliative care into the fast-paced, time-intensive, life-saving focused ED has proven difficult (Chan, 2005, Blackwell and Grudzen, 2014). The reasons for this are explored further in this and subsequent chapters.



#### **1.4.2 Time frame 2: 2008-2012**

##### ***Demographic changes and use of healthcare resources***

Part of the reason for the on-going evolution of palliative and emergency care in recent years can be attributed to changes in the population demographic. Across all developed countries people are living for longer, with current global estimates for those aged 60 and above doubling from 756 to 1400 million by 2030 (De Luca D'alessandro et al., 2012). In the UK it is those aged 75 and above who are the fastest growing age group, with a 1.2 million increase from 1.5 to 2.7 million between 1981 and 2007 (Beynon et al., 2011). A recent report estimates that by 2033 this number will reach 7 million (National End of Life Care Intelligence Network, 2010). The growth has been attributed to advances in medical science and treatments that are enabling people to live for longer with serious co-morbidities (National End of Life Care Intelligence Network, 2010, Bailey et al., 2011b).

Many people within this age demographic will be living for longer with a range of co-morbidities that require healthcare and social support (Formiga et al., 2008). The national end of life care audit released in the UK in 2008 was a seminal document highlighting the need for improved end of life care services for this ageing population (Burr, 2008). Approximately half a million people die annually in the UK, the majority of deaths occurring in hospital (58%), despite a preference of many to die at home (56% - 74%) (Burr, 2008). The majority of deaths in 2008 (over two thirds) occurred in people aged 75 and over; most of whom belonged to the 80-89 age group (National End of Life Care Intelligence Network, 2010). There is a healthcare impact in this changing demographic as people at the far end of the ageing spectrum (80-89 years) are also cited as the most likely to die in hospital (Ruth et al., 2010), despite 75% giving home as their preferred location to die (Davies and Higginson, 2004). In terms of inpatient bed use, older people in the UK account for 35.6% of total hospital admissions (National Confidential Enquiry into Patient Outcome and Death, 2009), and globally for 65% (Girio-Fragkoulakis et al., 2011).

As people live for longer with complex co-morbidities the incidence of deterioration and falls-related accidents has also increased (Scott, 2011). Access to community support services can be problematic (Wajnberg et al., 2012) resulting in increasing ED visits, particularly towards the end of life (Smith et al., 2012). Statistics for people aged 60 or over have shown that they account for 23% of ED attendances, and those aged 70 or over for 15.5% (Banerjee et al., 2013). Annual use of the ED by this population accounts for more than 43% of hospital

admissions (Banerjee et al., 2013), and comprises 68% of hospital emergency bed days (Imison et al., 2012).

In terms of palliative and end of life care needs, not only do older people present to the ED in their last year of life, but for some it is where terminal conditions are first highlighted. A recent report from the National Cancer Intelligence Network revealed that one third of all cancers in older people are diagnosed via the ED (National Cancer Intelligence Network, 2012). What is concerning about this for patient outcomes, is that those with cancers diagnosed through an emergency visit are much less likely to survive the next year (National Cancer Intelligence Network, 2012). The precise reason for these ‘diagnostic ED visits’ is not certain but likely propositions include the reluctance of older people to ‘bother’ their GP with their symptoms, or symptoms being dismissed as part of the ageing process when initially highlighted in the community (National Cancer Intelligence Network, 2012).

***Palliative care provision for older people in the ED: the impact of the admission***

Attendance to the ED by older people can be understood within three groups. For the first group, the ED visit is ‘appropriate’, in that it is in keeping with the traditional model of ED care, for example as a result of falls, elder abuse and delirium (British Geriatrics Society, 2008). For these patients the ED can also play an important role in the care of older people, acting as ‘*an interface between community and secondary care*’ (Burns, 2001, p.3). While seen as ‘appropriate’, visits to the ED by older people are more likely to occur via ambulance, to include more investigations and longer waits in the ED, and to result in a greater incidence of hospital admission than those in the 21-59 age group (Banerjee et al., 2013).

A second group may be approaching the ED for similar causes as the first, but their attendance indicates underlying palliative care needs, which is unsurprising given the overlap between geriatric and palliative care (Amella, 2003). As with palliative care, geriatric care is concerned primarily with ‘*fostering independence or control over life and preserving quality of life*’ (Amella, 2003, p.40). These goals are achieved through a multidisciplinary effort combining health and social care practitioners. Other recognised causes of admission to the ED that require both palliative and geriatric input include a lack of social support, deterioration in chronic co-morbidities, greater adverse reactions to medical input and general frailty and inability to cope alone at home (Aminzadeh and Dalziel, 2002, Hwang and Morrison, 2007). For this group, the traditional model of emergency care may be

inappropriate in its design, but appropriate in regards to the care and potential for service connections it can offer.

A final group in the older population presenting to the ED are those with palliative and end of life care needs. While there have been efforts to improve advance care planning, elderly palliative patients continue to present to the ED (Burr, 2008, Bailey et al., 2011b, Beynon et al., 2011). The reasons for palliative admissions vary and can include acute condition deterioration and poorly controlled or unanticipated symptoms, for example dyspnoea, fatigue, and exacerbation of pain (Geraci, 2006, Wiese et al., 2008, Barbera et al., 2010). Non-medical reasons include support breakdown, such as lack of out of hours services, communication collapse between services and patients and carers, and family panic or distress, which is often linked to physical and psychological strain (Worth et al., 2006). Care giver distress may contribute to failures to follow and implement care plans. There are also palliative care emergencies which carers may be unable to manage, such as acute haemorrhage, pain, acute dyspnoea, acute function loss, delirium and acute anxiety (Wiese et al., 2008, Schrijvers and Van Fraeyenhove, 2010).

The recognition and response to the needs of older palliative care patients by ED staff is vital as, regardless of cause or perception of the classification of 'emergency', palliative care admissions are distressing and can hasten death or decrease the quality of life (Schrijvers and Van Fraeyenhove, 2010). The increasing use of the ED by older palliative care patients raises questions about palliative care training and education of ED staff, as they must be equipped to meet the needs of those seeking emergency care (Grudzen et al., 2010). Treatment must be tailored to provide the desired care for physical needs, but must also respond to the psychological needs of the patient and their family, redirecting them to the most suitable location and healthcare team (Wiese et al., 2009). However, once in the ED, ED staff can be faced with the choice of prioritising care between a patient with palliative care needs and another ED attendee with more typically urgent needs, and in these cases palliative patients may be triaged as non-urgent (Smith et al., 2009).

A sad reality is that ED interactions often prove distressing for all involved. Staff reports reveal frustration that the level of care they are able to provide is inadequate to meet the care needs of the patient group (Kihlgren et al., 2005). The traditional ED focus is on the needs of the acutely injured and unwell, with an emphasis on resuscitation and stabilisation and this leaves staff ill equipped to offer palliative care (Richards, 2011, Lamba et al., 2012).

Palliative care, in contrast to the fast, efficient and occasionally abrasive ED model of care, focuses on building relationships with patients and families. The lack of prior relationships between patients, families and ED staff further complicates the development of trusting relationships. Additional challenges for ED staff faced with palliative care patients concern insufficient access to pertinent information (Banerjee et al., 2013), and a lack of training and experience to recognise and deliver a different type of ‘appropriate’ care (Gisondi, 2009, Lawson et al., 2009). Some reports found that older people could be isolated and discriminated against (often unintentionally) by healthcare staff in regards to the options offered to them in treatments and decision making (Bridges and Nugus, 2009, Banerjee et al., 2013).

### ***Healthcare and policy response to the demographic changes***

A number of policies regarding palliative and end of life care were developed in the UK in response to the demographic changes and healthcare outcomes outlined. In 2008, along with the publication of the end of life care audit (Burr, 2008) were two further seminal reports providing national commitment and strategy to improving palliative care: the NHS Next Stage Review (Department of Health, 2008b), and the End of Life Care Strategy (Department of Health, 2008a). The End of Life Care Strategy led to the National End of Life Care Programme which encouraged initiatives for improving community and acute care services to reduce unplanned hospital admissions and length of hospital stay (National Health Service, 2011, National End of Life Care Programme, 2012).

The National End of Life Care Programme launch in 2008 resulted in numerous local and national initiatives to improve end of life care. Examples included the Gold Standards Framework for Palliative Care (Gold Standards Framework, 2011), that works with palliative care specialists to help GPs and care homes staff to provide high quality end of life care, and a web based end of life register for health professionals set up by the South West Strategic Health Authority (Department of Health, 2010). The annual National End of Life Care Strategy provided further information on projects occurring across the UK (Department of Health, 2008a, Department of Health, 2009, Department of Health, 2010, Department of Health, 2011). Within the different projects were examples of: patient and carer involvement, joined up care, research, reducing costs, and ensuring that patients were in their preferred location of care (Department of Health, 2009, Department of Health, 2010, Department of Health, 2011). The ED however was rarely mentioned, other than as a place to avoid (Sam, 2011).

Some clinicians and researchers responded to the increasing use of the ED by the ageing population by developing ways to adapt the traditional ED model. One prominent example was the Silver Book (Banerjee and Conroy, 2012). This was released in 2012 as a guide to help reduce ED admissions and to improve the experiences of those admitted (Harris, 2012). Other examples include a multidisciplinary approach and an integration of specialist geriatric teams into the ED (British Geriatrics Society, 2008). Of particular interest to this research was the suggestion by the British Geriatrics Society in 2008 that the ED should consider redesign of the service from the patient's perspective as an integrated and accessible patient-centred environment (British Geriatrics Society, 2008). The inclusive approach with a view to redesigning services is inherent in the methodology used to undertake the current research.

Interestingly, specialist geriatric teams in the ED became more common in the UK, while there were less palliative care developments for older people in the ED during 2008-12. Conversely in the US, both geriatric and palliative care developed in the ED during this same time frame. In 2006 palliative medicine became a subspecialty of emergency medicine (Lamba and Mosenthal, 2010), and ED clinicians began to explore different methods of integrating the two (Wiese et al., 2009). This included ED-initiated, ED-based palliative care consultations (Waselewsky et al., 2009), exploration into the knowledge and attitudes of ED practitioners (Smith et al., 2009), training programmes (Gisondi, 2009) screening (Glajchen et al., 2011) and initiation of palliative care in the ED (Devader et al., 2011). New suggestions for care of older people in the ED included geriatric-only EDs that built on the paediatric model of ED care (Hwang and Morrison, 2007); which Chapter Two explores.

#### **1.4.3 Time frame 3: 2013 – January 2015**

This final section presents two pivotal changes that occurred within palliative and emergency care between 2013 and the present day in 2015, exerting a significant influence on the final stages of this thesis.

The legacy of the End of Life Care Strategy introduced in the previous time frame, was the creation of the National End of Life Care Intelligence Network (National End of Life Care Intelligence Network, 2013). The network works to improve collation and analysis of various aspects of data related to end of life care in the UK to help improve the 'quality and productivity of services' (National End of Life Care Intelligence Network, 2013).

### ***Palliative care crisis***

Since its first publication in the 1990s the LCP had become the most recognisable end of life care tool, supporting practitioners within the NHS and was largely used as ‘best practice’ across multiple healthcare settings (Broadbent, 2013). Then, throughout 2013, negative patient and carer experiences of the LCP began to emerge. Picked up and pursued by tabloid media, controversial and inflammatory headlines such as ‘*It was murder, says son of woman “starved to death” on Liverpool Care Pathway as he calls for police inquiry*’ (Smith, 2013) led to a campaign demanding its removal (Broadbent, 2013). The outcry led to an independent review undertaken by Baroness Neuberger (Williams, 2013). The enquiry resulted in a seminal and practice-changing document on end of life care in the UK, published in 2013 (Williams, 2013).

Entitled ‘More care, less pathway, a review of the Liverpool Care Pathway’ (Williams, 2013) the report identified numerous challenges with the guideline implementation and use. The taboo in the UK sounding the topic of death in recent years meant that, while many families were unable to accept or understand what was happening to them or their relative, staff members were often ill equipped to provide the care required. This was found to lead to misinformation and confusion. Confusion was further compounded by the divide between specialty palliative care and mainstream medicine, meaning that many generalist nurses and doctors were uncertain of how to apply the LCP, and many had not had basic training in palliative and end of life care. Some were also lacking communication skills to explain what was happening to the patients or their families. Of particular importance to the work of this thesis was the review’s findings concerning communication and care for the older dying patient. This was classed as the area of greatest concern, with reports of unlawful age discrimination in regards to consent and capacity (Williams, 2013).

The review also found that some of the recommendations within the LCP had not been updated in the years following its first iteration. This was partly due to the challenging nature of the topic, the frail and vulnerable nature of the patient group, and a multitude of ethical considerations, raised later within this study, that make research into dying matters a complex issue. Instead some areas of palliative care provision had developed over the years based on best practice and observation, for example nutrition and hydration. While there were instances where this was managed sensitively and the changing physiological needs of the dying patient clearly communicated to the families, hydration and nutrition was a strong area

of contention. The report found that negative experiences often referenced patients being denied fluids or food once they were 'put on' the LCP which actually advises that patients are provided with hydration according to their individual needs (Williams, 2013). A notable exception to limited research in end of life care is medication and medication administration which has steadily progressed since the work of Dame Saunders in the 1960s and 70s (Hanks et al., 2011). However, even here the report noted concerns with end of life care medication regimes that were occasionally implemented and administered without a proper review of the patient (Williams, 2013).

The report also documented many excellent examples of its use, with medical and nursing opinion largely in favour of the LCP, often citing it as one of the most helpful tools for improving care of the dying in recent years. However, despite the positive reports, the support that the LCP gave to staff and the fact that it was not the guideline at fault (but poor implementation, practice and lack of understanding regarding the document), the report recommendations stated that public opinion and mistrust was such that the LCP should be banned and removed from use by July 2014 (Leadership Alliance for the Care of Dying People, 2014a). The review contained forty four recommendations for responding to the concerns raised in the report to improve end of life care in the UK. A summary of the recommendations most pertinent to this thesis are:

1. The Liverpool Care Pathway should be replaced within 6-12 months of the report by July 2014, with an end of life care plan for each patient.
2. The name "Liverpool Care Pathway" should be abandoned and the term "pathway" avoided.
3. Decisions to continue or discontinue life prolonging treatment should not be made out of hours. Such decisions should be made during the daytime by the responsible senior clinician.
4. To aid clinicians in diagnosing dying, evidence based prognostic tools should be promoted. Clinicians should receive training and education in communicating the uncertainty around diagnosing dying.
5. All staff in contact with the patient should be trained in the appropriate use of nutrition and hydration at the end of life. Failure to support oral nutrition and hydration where still possible and desired should be viewed as professional misconduct.

6. It must be the responsibility of the senior clinician to document the meeting where an end of life care plan was first discussed with relatives. It should be documented that relatives were made aware that the patient is dying and that they were given the opportunity to ask questions.

The removal of the LCP had a number of consequences for practice, which impacted on the ED as well as on wards and the community. For many staff it was an issue of deskilling; a tool they relied on for guidance was now gone and many were uncertain of how they were now supposed to provide care to the dying. Following the review, the Leadership Alliance for Care of Dying People was established in 2014 to develop and redirect palliative and end of life care in the UK (Leadership Alliance for the Care of Dying People, 2014a). Among its recommendations were the ‘five priorities of care for the dying’. These priorities built on the findings of the review, responding to reports of lack of communication and involvement of patients and families in decision making processes. The priorities are:

1. The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person’s needs and wishes, and these are reviewed and revised regularly.
2. Sensitive communication takes place between staff and the person who is dying and those important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care.
4. The people important to the dying person are listened to and their needs are respected.
5. Care is tailored to the individual and delivered with compassion – with an individual care plan in place.

(Leadership Alliance for the Care of Dying People, 2014b)

For this research the removal of the LCP had both positive and negative connotations. While the review emphasises the importance and inclusion of the patient and their family, the guidance for clinical application is vague, and subsequent chapters demonstrate that many ED clinicians became uncertain about their role in the processes of care of the dying patient. A positive outcome from the review and removal of the LCP was the increased focus on research into palliative and end of life care for all conditions that was not present at the start of this study, as discussed later in this chapter. However, for the public, fear has been a very real factor. Negative experiences combined with inflammatory media reporting had widened



the rift between the public and the NHS. This thesis will later explore how staff and older palliative patients and carers struggled to develop trusting relationships, as visiting the hospital became a lot more frightening for many people with terminal conditions.

### ***ED crisis***

The four hour target which measures how long it takes from arrival to discharge from the ED, discussed earlier, has become one of the key benchmarks used to monitor ED performance in the UK (Blunt et al., 2015). There have been growing challenges placed on the ED as it has increasingly become the first port of call for many people in health-related crisis, despite efforts to reduce pressures on the department and to keep care in the community (Ford et al., 2013). Towards the latter end of this research study, reports of an 'A&E crisis' across the NHS began to surface in the media, based on hospitals failing to meet the four hour target (Triggle, 2015).

To understand the impact of the target it needs to be recognised that the hospital system is a complex one that relies on the through flow of patients in and out of the hospital. To admit patients into the hospital from the ED sufficient ward and bed spaces and staffing need to be available. The four hour target has had a knock-on effect on the functioning of the rest of the hospital system, and indeed in to the community, particularly given the financial 'squeeze' which has reduced access to resources and placed greater pressure on staff (Blunt et al., 2015). In the ED staff must triage, assess, treat and discharge patients to the most suitable location, either discharge or admission, within the allotted four hours. Short stay observation wards were created for patients who were not well enough to be discharged. These created controversy and were labelled by some as a way to manipulate numbers and report that targets are being met (Save the Mid, 2013).

As the ED worked faster so the rest of the hospital had to respond, clearing bed spaces to bring in the new patients. One response was to bring patients to the first available bed space as outliers, even if it was the 'wrong' ward. This impacted on the medical and allied professional teams who then had to cover more physical space, with wards not always fully equipped to provide the right care. Recent ward closures and restricted bed spaces have also been blamed for the increased pressure in the ED (Citizennews, 2015).

As emphasis on clearing bed spaces increased, rushed and sometime premature discharges occurred. Premature discharge can be dangerous for patients who are without proper community support and readmission via the ED, particularly for older patients is not uncommon (British Medical Association Patient Liaison Group, 2014). Each year all of the challenges outlined above increase in the winter months, where colder, wetter weather exacerbates chronic conditions or can lead to falls and injuries in older, frail people (NHS England, 2014).

By early 2015, at the time of writing this thesis, there had been an relentless focus in political debate and across the media on the four hour target and the implications for the NHS of the ability or inability of EDs to meet it (Blunt et al., 2015). Similarly to the LCP, this is an emotive topic and one that often has damning media headlines attached to it, for example: *'A&E crisis explodes: Off-duty nurses are begged on Twitter to work longer, casualty wards likened to "packed nightclub" while TENTH hospital declares "major incident"'* (Borland et al., 2015). A 'major incident' is actually classified far less distressingly than the headline suggests, as *'any event whose impact cannot be handled within routine service arrangements. It requires the implementation of special procedures by one or more of the emergency services, the NHS, or a Local Authority to respond to it'* (Department of Health, 2007).

Political parties have argued over the 'state' of the NHS, the degree to which it is in crisis and the impact of the ageing population (Sparrow et al., 2015). In March 2015 a political briefing was published by the Nuffield Trust in the form of a report fully exploring the actual figures relating to the target, and offering an objective perspective (Blunt et al., 2015). The report confirmed that EDs are functioning under increased pressure, but refers to the focus on the four hour target as 'disproportionate' (Blunt et al., 2015, p.1).

The report showed that, in the ten years since the introduction of the four hour target, ED attendances have increased by 32% from 16.4 million in 2003/4 to 21.8 million in 2013/14. While this may look alarming, these figures are proportionate to the predicted increase, based on population changes. In addition many of these admissions were to access minor injuries services due to the development and increase in services available via the ED, rather than for admission and care of chronic conditions.

The ability of EDs to transfer 95% their patients out of the department within the allotted time frame has not been met since the summer of 2013. The incidence of patients waiting over four hours for admission to hospital has almost trebled, and delayed ambulance

handovers in the ED have increased by over 70%. However, the report stated, the media had misrepresented the ‘crisis’. Actual figures for 2014 showed that the average performance against the target was actually 92%, while the average time spent in the ED before admission to hospital was three hours and forty three minutes, and the average time before discharge home was two hours and seventeen minutes (Blunt et al., 2015). Significantly for this thesis however, the report did find that for people aged 75 and older, waits tended to be over an hour longer than for younger people (Blunt et al., 2015).

The report questioned the use the of term ‘crisis’ and found that delays were not the fault of the ED, but rather that challenges stemmed from the safe and quick discharge of patients back home from the hospital (Blunt et al., 2015). This is an issue that has been exacerbated by increased medical and social needs of an ageing population with co-morbidities, as discussed throughout this chapter. Similarly to the two reports discussed within the palliative care crisis (Williams, 2013, Leadership Alliance for the Care of Dying People, 2014a), the Nuffield Trust report offered a series of recommendations (Blunt et al., 2015, p.2). These are included in full below due to their relevance to this thesis:

***‘Focus on getting things right in primary care to enable prevention to work – but be realistic about how much can be achieved. Policy-makers can help to boost primary care through supporting moves to build up the skills and capacity of health care professionals to provide high-quality urgent care services outside hospital.***

***Remove some of the complexity of different services that has been built into the system, and which confuses the public and NHS staff. Creating a single point of access to community services for patients and GPs would be one way to achieve this.***

***Focus on the way patients move through hospital – and be realistic about what policy-makers can and can’t do. Policy-makers can help by investing in care outside hospital, but they must let providers find solutions that work for their patients.***

***Foster a better understanding of the way that local systems work. Promoting better data outside hospital and encouraging the development of systems modelling in individual trusts would be an important start.***

***Take a longer-term and broader view of performance in A&E – and consider clustered randomised controlled trials of alternative performance measures. Policy-makers***

*should encourage the adoption of a set of richer performance indicators to sit alongside the four-hour target, which could be trialled in certain areas’.*

As the subsequent chapters within this thesis demonstrate, all of these recommendations have direct repercussions for the development of strategies to improve palliative care experiences for older palliative patients, their carers and staff in the ED. Chapter Eight takes up this theme following the conclusion of the research and the presentation of the methodological, clinical and political implications of the research.

## **1.5 Critical reflection**

In this final section the narrative moves to the first person critical reflection, reviewing the implications of the social context and background on the conduct of this thesis.

### **Defining the study problem**

At the beginning of this chapter I presented and reviewed the definitions for the three intertwined threads that make up the research challenge: providing high quality palliative care in the ED for older people.

The challenge of defining palliative care is a theme found throughout this thesis, reflecting the complications discussed within the literature. Although the actual definitions are presented as clear statements, the route to selecting them was difficult and I spent much of the first two years of this study grappling with the changing understanding of palliative care and how it affected the work of this thesis. I sought the opinion of various palliative care clinicians as well as reviewing the literature. In retrospect, though I now have confidence in the definitions and the clinical understanding of palliative and end of life care used within this thesis, the route to my understanding was a difficult one, aided by publications referenced earlier in this chapter.

Similarly challenging was clarifying the age that constitutes ‘old age’ for this thesis. Sixty five was selected for the reason given within the chapter, but at times I questioned if this was too young. At times I felt that applying an age to the term ‘old’ was arbitrary as there are so many factors to be considered such as frailty, general health and capacity and retirement. During the research I found that some of the ED staff objected to the ‘65’ label, stating that they had cared for younger people who could appear far older, with the reverse also being true. Ultimately however, the decision was based on the most common understanding across the literature, thereby enabling the inclusion of important publications.

## **Time frames**

As stated, the context for the study was broken into three time frames that represented significant changes in palliative and emergency care that influenced this thesis. In the following sections I discuss the stages and progress of this study in relation to those time frames.

### *1960-2007*

I qualified and began practising as a nurse in 2007. I had witnessed little in the way of formal classroom-based education into end of life or palliative care and the majority of my awareness had come from clinical placements. Despite this I began working at St Christopher's Hospice as outlined in the prologue and it was here that I became aware for the first time of the need for emergency care for palliative care patients and the challenges inherent within the interactions for patients carer and staff.

### *2008-2012*

A significant influence in my undertaking of the study was the changes in policy and practice stemming from the End of Life Care Strategy in 2008. I observed that the patients and carers within my care were requiring the use of the emergency services but that the ED was largely overlooked by the new trend of developments. In conversation with colleagues I found that they were feeling vulnerable and unskilled. In conversation with the principal supervisor for this thesis, Dr Grocott, I was encouraged to undertake this thesis as a means for raising the profile of the palliative care patient and the ED staff and identifying ways for improving their experiences of care. This was challenging for, as discussed in the following chapters, practitioners and research funders were not immediately aware of or willing to accept that this was a very real issue. It took a further three years until the research officially started in 2011, and even then there was initial reluctance and confusion in response to the study's aims from both healthcare and public bodies.

### *2013-2015*

In many ways this final time frame has been the most significant to the thesis. The LCP, discussed further in Chapter Four, was referenced frequently by ED staff in regards to their role in palliative care provision in the ED. Its removal shook the ST Thomas' ED where the research was based and my role in the process altered with it, with staff often asking me for advice while I was in the department gathering data. This is discussed further in Chapter Eight. The ethical application for patient and carer inclusion in the study was submitted in

early 2014. Here again, the response of the staff at St Thomas' ED to this study was more positive than to the initial set up in 2011, as the LCP review had demonstrated the need for palliative care research.

Personally there have been many challenges due to the uncertain undercurrent of change in the NHS in both palliative and emergency care, and as the impact of an ageing demographic with complex conditions is still being understood. This chapter has set the social, clinical and political scene that the work was conducted within, and as of early 2015, it is still uncertain quite how palliative care will look in the NHS. Globally this issue is being explored, and policy and practice leaders are pioneering new ground for its delivery. Therefore this critical reflection concludes with the observation that the ground is rich for development and research, to which the rest of the thesis seeks to add.

## **1.6 Conclusion**

This chapter started with the observation that the research undertaken in this thesis stems from three separate threads that have become intertwined within a complex social and medical setting: palliative care for older people, their carers and staff within the ED. The narrative has shown that this research is occurring within a time of national and system wide challenges. The focus has been on objective factual information, but within the chapter it can be seen that there are various issues preventing staff from meeting the needs of older palliative patients and their carers.

Over the next eight chapters the narrative leads these threads through an EBCD project to explore these factors and to work with older palliative patients, their carers and ED staff to improve their shared experiences. This starts with Chapter Two which appraises the experiential literature that informed the development of this research.

## **CHAPTER TWO: INFORMING THE STORY**

### **2.1 Introduction**

The previous chapter showed that, although UK-based policy advocated improving community care to reduce ED attendance for palliative care patients (Scott, 2011), admissions were, and are still occurring (Shreves and Marcolini, 2014). This suggested that unless all palliative-related admissions could be prevented, the ED needed to adapt its model to improve care in this area. Before embarking on the EBCD study presented within this thesis, it was important to research further into the literature to gain a better understanding of the opinions and experiences of those involved. Experiential literature was of particular importance as this thesis aims to improve palliative care encounters in the ED, and the literature was used to inform the data collection tools (discussed in Chapter Four).

The purpose of this narrative review of the literature was, therefore, to inform the research by exploring what was already known and what was missing about provision of palliative care for older people in the ED according to the experiences and perspectives of the patients, their carers and the ED staff.

### **2.2 Chapter overview**

The thesis is led through the processes of finding and selected the literature before moving into a narrative review of the findings. The conclusions of the narrative review are then presented as they pertain to this study. A first person critique and reflection of this stage of the thesis is provided, before concluding and leading into the following chapter.

The prologue explained that this thesis is written and presented as a chronological retelling of the research story, with the inclusion of pertinent literature as and where it emerged during the process. For this reason, as the literature review was conducted in 2012, this chapter contains only material was available at this stage. All new work emerging over the following two and a half years is introduced in subsequent chapters.

### **2.3 Searching the literature**

The narrative review applied a recognised method of planning the search, critically selecting relevant papers, analysing them thematically and then applying the findings to this thesis (Beecroft et al., 2007). The review process was systematic in that it followed a structured method in order to draw together what was known from research (Gough et al., 2012). A focused search strategy saves time and provides structure, thus avoiding time wasted sorting

through unrelated literature (Beecroft et al., 2007). The search strategy used within this thesis consisted of four steps leading up to the review of selected papers (Beecroft et al., 2007).

Step 1: A preliminary search to identify key search terms and gain insight into the scope of available literature.

Step 2: Compile key search terms into categories

Step 3: Select search parameters and sources

Step 4: Process of critical selection

### 2.3.1 Step 1: Preliminary search for key terms

As stated it was unclear how extensive the body of literature would be relating to older palliative care patients in the ED. This search and review was the first activity of the study and the full extent of confusion about defining and applying palliative care was not yet fully understood. Therefore a preliminary search was run on the Ovid Medline database using the terms ‘palliative care’ and ‘accident and emergency’. The search provided insight into terminology, but also suggested that there was limited information available pertaining to a combination of the three topic threads under exploration. Table 1 below presents the final search terms used according to category.

**Table 1: Search terms and categories**

Category 1: Palliative terms		Category 2: Emergency terms		Category 3: Gerontology terms		Category 4: Interventions
Palliative care OR Palliation OR End of life OR End of life care OR Terminal care OR Palliative patient	A N D	A&E OR Accident and emergency OR Accident and emergency department OR Emergency department OR ED OR Emergency care OR ER OR Emergency	A N D	Elderly care OR Gerontology OR Geriatrics OR Older people	A N D	Experience-based Co-design OR Participatory action research OR Teaching OR Education OR User involvement



### **2.3.2 Step 2: Compiling the terms into categories**

One method for designing a directive search is to break down the elements into categories. There are different models but the most common is the 'PICO' approach (Beecroft et al., 2007); an acronym that divides the question into four sections:

- Patient/problem
- Intervention
- Comparison
- Outcome

As there was not a specific question being asked, this search drew on the PICO approach by using four categories but instead named them according to typology. Table 1 contains the search terms within their four categories, which were:

1. Palliative terms: terms that related to palliative care or parts of palliative care.
2. Emergency terms: variations on the emergency department based on the different country's terminology.
3. Gerontology terms: terms related to older people.
4. Interventions: a variation on types of interventions that include user involvement, or teaching and education.

These categories were then run in various combinations using the strategy outlined in the next section.

### **2.3.3 Step 3: Search parameters**

Different parameters were applied to the search to limit or expand its remit. First, the terms within each category were applied systematically in different combinations using the Boolean operators 'OR' and 'AND' (Beecroft et al., 2007). The same searches were run through five different databases: Ovid Medline, Embase, British Nursing Index, Science Direct and Google Scholar.

Limitations used to narrow the search and obtain appropriate papers included a year time frame limit of 2000-2012, restricted research to human subjects and was available in English. The time period was selected to obtain papers applicable to recent policy and changes in the healthcare setting discussed in Chapter One, most notably the ED. The focused search containing Categories 1 to 3 yielded only four papers which referred directly to palliative care for older patients in the ED. This result necessitated a broader search. By combining the four

categories in different ways, a larger body of literature pertaining to issues which inform this study was gathered exploring:

- Palliative care in the ED
- Older people in the ED

Once identified and selected using the criteria outlined in the next section, papers were exported to the reference management system EndNote and grouped according to their content, for example palliative care in the ED. This grouping not only enabled a systematic approach to be taken when undertaking the narrative review, but also provided a logical method of compiling and managing the literature throughout the thesis.

#### ***Updating the search and grey literature***

To ensure that the research was influenced by emerging literature, the search was re-run on the databases every six months. In addition Rich Site Summary (RSS) feeds and notifications were put in place to provide ‘alerts’ regarding new literature. This proved to be an efficient method of gathering good quality papers and policy documents as they emerged.

As well as the clinical and academic literature there were a number of key organisations whose websites were also reviewed on a regular basis for important reports and papers. These organisations were the National Council for Palliative Care, the National End of Life Care Intelligence Network, the National End of Life Care Programme, The Gold Standards Framework and The King’s Fund.

#### **2.3.4 Step 4: Process of critical selection**

The process of critical selection for the narrative review was an iterative one. The narrative review, as stated, intended to find out the main themes and challenges causing negative or positive experiences in the ED for older people, their carers and staff. Therefore, unlike most literature reviews, empirical intervention studies were of less relevance than exploratory qualitative papers. However, papers which sought to improve aspects of clinical care were still included if they contained experiential data which could enhance the review.

The key inclusion criteria were experience and applicability to the topic. For example, a paper could be provisionally included if it contained new or key information related to the three threads (palliative care, older people, the ED), but came from a weak source. However,

if no other source corroborated this information then weaker sources were excluded. For inclusion in the review, literature had to sit within one of the criteria below:

- Clear and pertinent relevance to experiences of palliative care for older patients in the ED in a high quality study (quantitative or qualitative)
- Clear and pertinent relevance to experiences of palliative care for older patients in the ED in a lower quality study (quantitative or qualitative with concerns about reliability and/or validity)
- Clear and pertinent relevance to experiences of palliative care for older patients in the ED (discussion papers)

As stated, the literature search identified only four papers that focused specifically on palliative care for older people in the ED. Table 2 presents a summary of the characteristics of these four papers.

**Table 2: Characteristics of the four papers related to palliative care for older people in the ED**

Reference	Country of origin	Type of paper	Applicability
O'Mahony, S., Blank, A., Simpson, J., Persaud, J., Huvane, B., Mcallen, S., Davitt, M., Mchugh, M., Hutcheson, A., Karakas, S., Higgins, P. & Selwyn, P. 2008. Preliminary report of a palliative care and case management project in an emergency department for chronically ill elderly patients. <i>Journal of Urban Health</i> , 85, 443-451	US	Report of a pilot study	The paper reports on work directly linked to the needs of older palliative patients in the ED.  However, it is from the US so transferability of findings may not be possible.
Grudzen, C., Richardson, L., Morrison, M., Cho, E. & Morrison, R. S. 2010. Palliative care needs of seriously ill, older adults presenting to the emergency department. <i>Academic Emergency Medicine</i> , 17, 1253-1257.	US	Qualitative cross sectional survey	The paper reports on qualitative work exploring the needs of older palliative care patients in the ED.  However, it is from the US so transferability of findings may not be possible.

Kompanje, E. J. O. 2010. The worst is yet to come. Many elderly patients with chronic terminal illnesses will eventually die in the emergency department. <i>Intensive Care Med</i> , 36, 732-734.	The Netherlands	Editorial	The content of the editorial mirrors that of this thesis and refers to data from the western world.
Beynon, T., Gomes, B., Murtagh, F. E. M., Glucksman, E., Parfitt, A., Burman, R., Edmonds, P., Carey, I., Keep, J. & Higginson, I. J. 2011. How common are palliative care needs among older people who die in the emergency department? <i>Emergency Medicine Journal</i> , 28, 491-495.	UK	Quantitative retrospective hospital admissions data analysis	This paper reports on findings, from the same study site where this study was based pertaining to older palliative patients. While it focuses on those who die, the paper raises the issues of palliative care needs in the ED of older people.

As the body of literature was so small, the search was extended to secondary literature which related to experience of two elements of the topic: palliative care in the ED or care of older people in the ED. Although this wider body of literature was not directly relevant to the full research question of this thesis, it held meaning and insight into aspects and potential barriers to provision of palliative care in the ED for older people that could inform the narrative review and that the study could draw on. To ensure that the papers selected held clear and pertinent relevance to the thesis, further inclusion and exclusion criteria were developed and applied to the two additional elements in an iterative fashion.

The inclusion criteria for literature related to palliative care in the ED is shown in Table 3. At the time of conducting this narrative review, the focus of this thesis was on palliative care for people in the last year to six months of their life, rather than those dying patients in the ED. This was for two reasons. First, because there is a difference between the nature of how general palliative care and specific end of life care are seen and delivered, as shown in the definitions discussed in Chapter One. Second, this study's methodology required the continuing participation of patients and carers, and therefore the informing literature needed to be relevant to their experiences. However, as the thesis goes on to reveal, ED staff in their interviews were actually often more concerned with dying patients. Although the search was then repeated to include papers focused on dying patients to inform later stages of the research, the critical reflection considers the impact on the study of excluding these data in the early stages.

**Table 3: Inclusion/exclusion criteria for literature related to palliative care in the ED**

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>• Experiential research with direct applicability to the thesis topic</li> <li>• Intervention studies with direct applicability to the thesis topic</li> <li>• Discussion papers with direct applicability to the thesis topic</li> </ul>	<ul style="list-style-type: none"> <li>• Literature not available in English</li> <li>• Unable to access full text</li> <li>• Literature specifically focused on death or dying, unless it extends to palliative care</li> <li>• Literature focussed on outcomes as these data provided little on existing practice</li> <li>• Letters to journals unless they were applicable to the thesis topic</li> <li>• Literature focused on trauma care</li> <li>• Literature focused on reasons for admission</li> </ul>

The inclusion criteria for literature related to care of older people in the ED is shown in Table 4. These criteria were more restrictive than those for palliative care as, despite the overlap between palliative care and gerontology discussed in Chapter One, there are also significant differences. These differences were shown to impact negatively on the degree of applicability to the thesis topic, for example the scope found in studies developing ED-based needs assessments.

**Table 4: Inclusion/exclusion criteria for literature related to care of older people in the ED**

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>• Experiential research with direct applicability to the thesis topic</li> <li>• Intervention studies with direct applicability to the thesis topic</li> <li>• Discussion papers with direct applicability to the thesis topic</li> </ul>	<ul style="list-style-type: none"> <li>• Literature not available in English</li> <li>• Unable to access full text</li> <li>• Literature focused on ways to avoid ED admissions</li> <li>• Literature focused on attendance numbers</li> <li>• Literature focused on place of admission to the ED, e.g. residential care home</li> <li>• Admission due to non-chronic/palliative care reason, e.g. trauma, injury, alcohol</li> <li>• Intervention studies developing assessment tools that are not applicable to the thesis topic</li> <li>• Reviews containing data predating the introduction of the four hour breach rule in 2000</li> </ul>

The process of selection and rejection, along with the final categorisation for papers related to palliative care in the ED and care of older people in the ED based on the criteria above, is shown in Figures 2 and 3. Once selected, the papers were further divided into groups as shown. These figures exclude the papers identified during the initial search as they were not subjected to the same search parameters.

Figures 2 and 3 showed the initial yield of papers found in the secondary search. Table 5 presents the grouping of all the findings. In total 70 papers were found that contained a large enough degree of applicability to the topic to be included as part of the wider body of knowledge informing this thesis. Of those 70, only those related to experiences of palliative or elderly care in the ED are included in the narrative review (Groups 1 to 5). All the papers were placed into groups to help focus the review and draw out useful findings about the likely challenges in the ED regarding palliative care (Table 5).

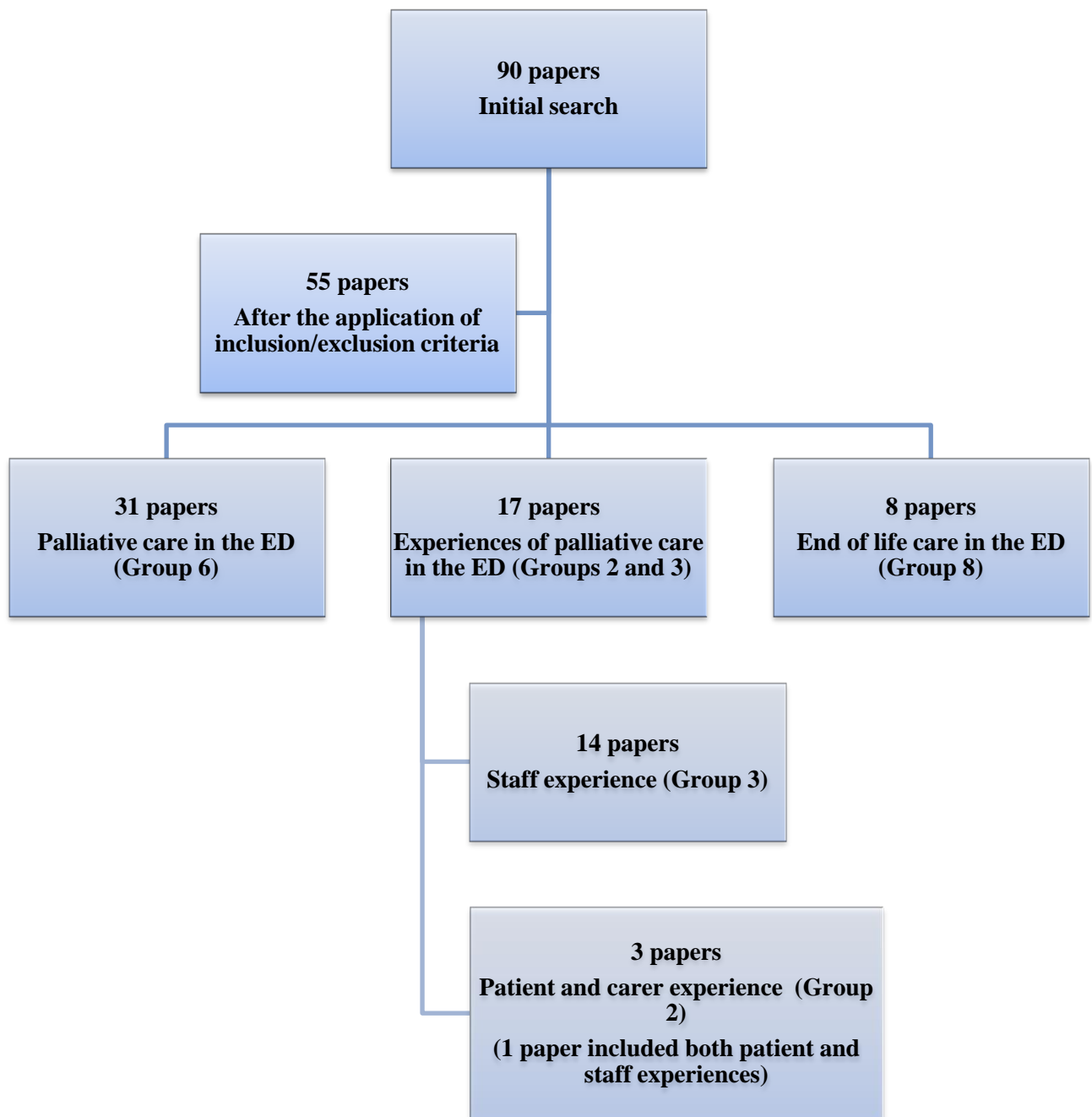
There were 31 papers directly related to palliative care in the ED (Group 6), and four related to care of older people in the ED (Group 7). These 35 papers are not included in the narrative review for this chapter as it was not until much later in the study that this literature was actually considered and applied. However, their numbers are included in Figures 2 and 3 and Table 5 in order to show the paucity of literature available and the geographical spread of research related to this topic. In addition, many of these papers informed the previous chapter and add nothing new to the narrative review, which as stated, is based on findings from lived experiences. The eighth group found in Table 5, care of the dying/dead in the ED, has already been explained. It has been included in the table to demonstrate knowledge of the existence of this literature, but its exploration is included later in the thesis.

An interesting finding within this small body of literature was that documentation of experiences was very limited. In addition, within palliative care experiences in the ED (Figure 2) the staff literature was considerably larger than that of patients, with fourteen staff papers compared to three for patient experience, one of which was also included in the staff group. Within care of older people in the ED (Figure 3), the patient experience has been explored more than staff: seven papers on patient experience compared to two on staff. A possible reason for the imbalance in the palliative care literature is the difficulty, elucidated in Chapter One, of engaging palliative care patients in research as highlighted within this study in Chapters Five to Eight. The body of literature about older people in the ED was

smaller than that of the palliative care literature, and this may have been due to the search parameters, or to a then lack of recognition of the unique needs of older people in the ED.

Table 5 shows not only how few papers were found, but also contains the country of origin of the literature. An interesting feature of the papers included in the review was the geographic spread, with all papers from the western world. Given the setup of medical services and the western phenomenon of an ageing population discussed in Chapter One, this is perhaps not surprising. However, one of the challenges of this early stage was the limited data from the UK. Although there were 15 papers from the UK, some focused on the acute setting rather than the ED specifically. In addition there were no staff experience papers looking into care of older people in the UK. In contrast 39 of the 70 papers stemmed from the US, possibly due to the status of palliative medicine as a subspecialty of emergency medicine.

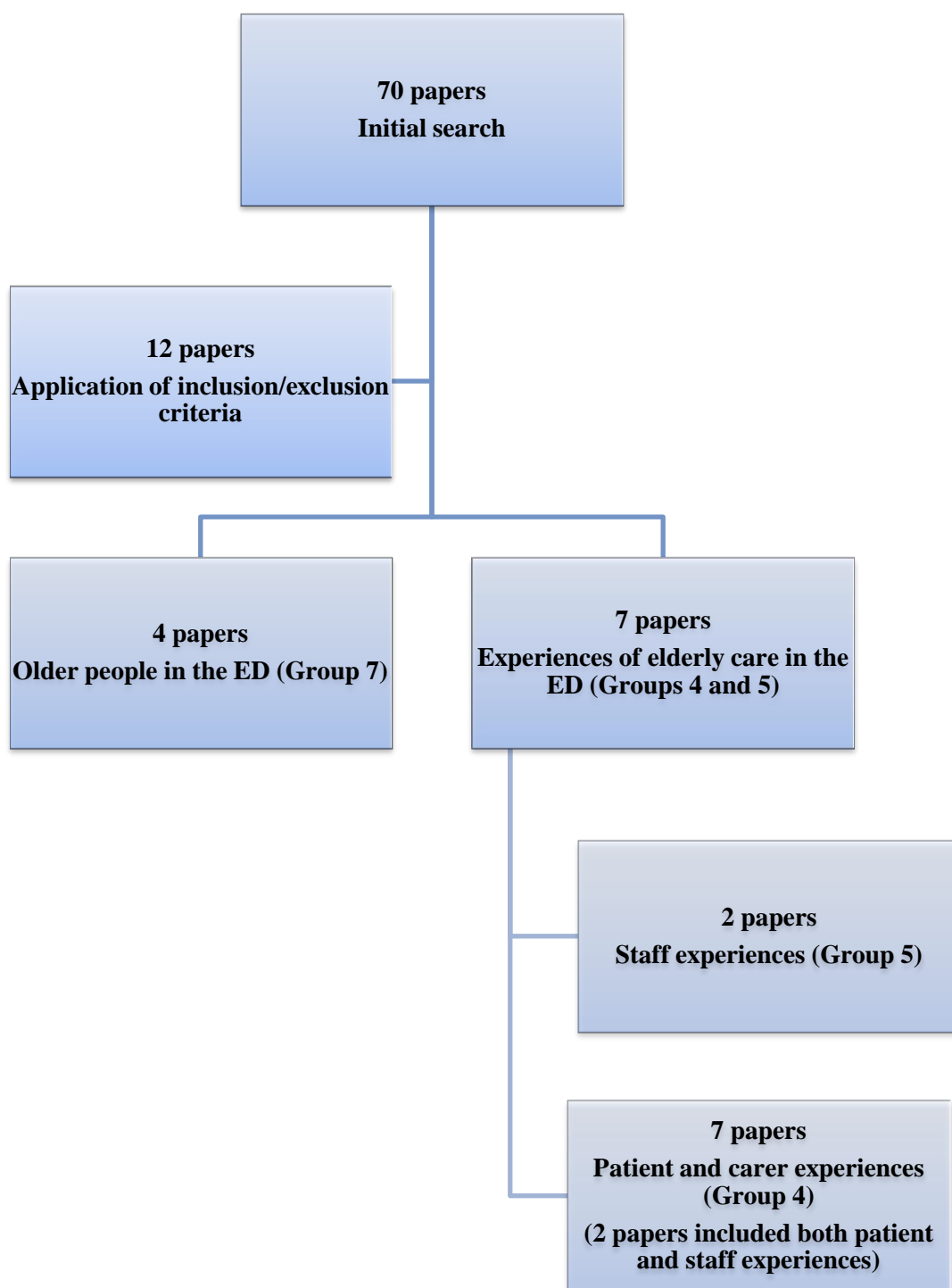
**Figure 2: Selection and categorisation of literature related to palliative care in the ED**



Note: For definition of the Groups please see text below and Figure 8



**Figure 3: Selection and categorisation of literature related to care of older people in the ED**



Note: For definition of the Groups please see text below and Figure 8

**Table 5: Grouping of the literature**

Number	Group	Number of papers	Country of origin
1	<b>Palliative care for older people in the ED</b>	4	Netherlands = 1 UK = 1 US = 2
2	<b>Patient/carers experiences of palliative care in the ED</b>	3 (includes one UK paper from group 3)	UK = 1 US = 2
3	<b>Staff experiences of palliative care in the ED</b>	14	Australia = 1 France = 1 UK = 3 US = 9
4	<b>Patient/carers experiences of elderly care in the ED</b>	7 (includes both staff papers from group 5)	Australia = 1 Canada = 1 Iceland = 1 New Zealand = 1 UK = 3
5	<b>Staff experiences of elderly care in the ED</b>	2	Canada = 1 UK = 1
6	<b>Palliative care in the ED</b>	31	Australia = 3 Canada = 1 France = 1 Germany = 1 UK = 5 US = 20
7	<b>Care of older people in the ED</b>	4	Australia = 1 UK = 1 US = 2
8	<b>End of life care in the ED</b>	8	France = 1 UK = 2 US = 4 Multinational = 1 (Australia, Canada, Sweden)

## 2.4 Narrative review of the literature

The narrative review was undertaken to identify the main themes of barriers, attitudes and challenges in the provision of palliative care to older people in the ED as identified through the experiences of patients, carers and staff. The review first explores the four papers from Group 1 separately to highlight the challenges in fully understanding the depth of the research problem at the start of this thesis. Then the review is led through the experiences found within the literature in Groups 2 to 5.

#### **2.4.1 Group 1: Palliative care for older people in the ED**

Three papers focusing on palliative care for older people in the ED explored different angles of this provision of care (O'Mahony et al, 2008, Grudzen et al., 2010, Beynon et al., 2011) and one was a discussion paper (Kompanje, 2010). The only UK-based article was a retrospective analysis of routine hospital data from 2006-7, conducted at two inner-London teaching hospitals which sought to identify the prevalence and nature of palliative care needs of people aged 65 and over in the two EDs (Beynon et al., 2011). The findings showed that the attendance rate for all age ranges was 21.3%, but admissions of the over 65s from the ED were much higher at 51.5%, most of whom had a record of recent contact with healthcare services. One hundred and two people aged 65 or older died in the ED during 2006-7, over half with a diagnosis signalling palliative care needs, though only eight were known to palliative care services. There was no record of end of life or advanced care planning tools used, which could indicate either a lack of recognition or poor documentation. Beynon et al (2011) revealed potential gaps in ED staff knowledge of palliative care as patient needs did not appear to be recognised or acted upon. ED staff recommended exploration of end of life care training needs to equip them to respond to the increasing use of the ED by palliative patients and families. Beynon et al (2001) also suggested an aspect of service re-design in the ED around development and use of triggers for referral to palliative care services.

Such an approach had already been piloted and is reported in one of the two US studies (O'Mahoney et al, , 2008). Here, the pilot study team worked with chronically ill older people with palliative care needs using an in-depth consultation to identify needs and then link them to appropriate services (O'Mahony et al, 2008). O'Mahony and colleagues (2008) reported that the system increased the likelihood of patients dying in their preferred location, but did not reduce subsequent ED attendances. The trial is an example of the advancements in palliative care in the ED in the US compared to the UK.

The needs of staff and patients were explored to varying degrees in the third and fourth papers in Group 1. Older palliative patients' care needs were explored in a US based cross-sectional structured survey (Grudzen et al., 2010). Needs were assessed from data of 50 functionally impaired adults aged 65 and over with a chronic, terminal condition. The findings showed that many patients struggled with the financial implications of their conditions, struggled to access care and had symptom control needs that were both physical

and psychological; their carers often struggled to provide for their needs. The authors (all of whom were ED physicians) concluded that palliative care can be delivered alongside curative or life-prolonging treatment, but that in-depth needs assessments can be time consuming and in some cases may not be clinically feasible. This study gave insight into some of the issues that patients might be admitted with, but not the experiences or preferences about *how* they are cared for in the ED.

The final paper in this group was a discussion on the plight of older chronically ill patients in the ED in the western world (Kompanje, 2010). Concerns were raised about the ED physician's responses and potential negative attitudes towards older palliative patients in EDs in regards to decision making, particularly around the provision of life-saving treatment (Kompanje, 2010). Decisions to remove life-saving treatment in the ED had included 'old age', 'underlying disease expected to be fatal in following six months' and 'recovery but expected quality of life unacceptably poor' (Kompanje, 2010). This type of rationale could be understood within the context avoiding unnecessary treatment. However, as such decisions were often made within hours of the patients arrival in the ED, it presented, Kompanje asserted, a distressing image of older people being admitted to the ED simply to die (Kompanje, 2010).

The narrative emerging from these first four papers was one in which practitioners in the ED were becoming aware of a growing incidence of a new type of patient group whose needs were not fully understood, and uncertainty about how to respond to them. Thus far however, the narrative has been sparse on the opinions and perspectives of the patients, carers and staff, particularly in the UK. Therefore the review now turns to the secondary literature to explore these aspects of care for older and palliative care patients in the ED.

#### **2.4.2 Narrative review of Groups 2 to 5**

The narrative review now turns to the secondary literature, drawing out what was known about the delivery of palliative care for older people in the ED. These papers were a mix of qualitative and opinion and the focus of the rest of the review is on the commonalities and gaps in the knowledge base at the time of starting this study (2011-12).

### ***Physical environment***

The ED environment as a whole was seen as a barrier to the provision of care by ED staff (Heaston et al., 2006, Kelley et al., 2011), and cited as a factor for negative experiences by patients (Richardson et al., 2007, Kelley et al., 2011). Discomfort from trolleys, noise, and frantic activity was often distressing to older and palliative patients (Gordon et al., 2010, Kelley et al., 2011). These are not unanticipated factors given the traditional remit of the ED, but there were also instances where patients felt that staff used the environment to put them out of the way and out of sight. This included patients who were suffering with what the author described as ‘subtacular’ conditions, meaning conditions opposite to trauma cases that required fast and invasive life-saving treatments: the ‘spectacular’ (Bailey et al., 2011a). ‘Subtacular’ patients, with less clear trajectories who do not require resuscitation and are chronically unwell may often be placed into a corner bed, with curtains drawn. There was less carer support, less face to face nurse contact, and less sharing of information with carers compared with the treatment of patients who died due to trauma (Bailey et al., 2011a, Couliota et al., 2012).

### ***Communication and information***

For ED staff the barriers to providing palliative care were not only exacerbated by the physical environment they were working within, but also the systems and processes. This included access to key medical information to aid decision making (Kelley et al., 2011, Lamba et al., 2013), access to and contact with palliative care services (Lamba et al., 2013) and communication with community and inpatient services who had pre-existing knowledge and relationships with the patients and their carers (Smith et al., 2009). Ironically, although ED staff acknowledge these barriers to their practice, their own provision of information and general communication was frequently referred to by both older and palliative patients and carers as lacking (Gordon et al., 2010, Smith et al., 2010a, Kelley et al., 2011). Some older patients felt this was to be expected and were willing to receive only what was provided, seeing relinquish of control as part of the process (Richardson et al., 2007). For others however, this was distressing and added to already high levels of anxiety (Way, 2008, Way et al., 2008). The issue of waiting in the ED was raised as an indicator for negative experiences by patients and carers, but here again, regular and informative communication by staff could ease distress and make waiting easier (Gordon et al., 2010). Repetition of questions and requests to retell their story were also a communication frustration for patients and carers (Way et al., 2008, Gordon et al., 2010). Exploration of the patient story does appear to be

limited to medical problems; one study found that spirituality was an important factor for palliative care patients that was left unexplored by staff who may have felt that this was outside of their remit of care (Grudzen et al., 2011c).

### ***Roles and understanding of palliative care in the ED***

The remit of palliative care for older people in the ED was a contentious factor throughout the experiential literature. A lot of palliative and elderly care admissions are the result of breakdowns in other parts of healthcare systems, difficulties in accessing services leading to deterioration, or care giver distress and inability to cope (Smith et al., 2010a, Grudzen et al., 2011c). Entering the ED is for many patients undesirable but seen as a safety net when all else has failed (Grudzen et al., 2011c). However, on arrival to the ED not all patients and carers know what to expect and may not be clear about their own plans and preferences for their care (Way et al., 2008, Kelley et al., 2011). This appeared to create a distressing situation for staff who could be left making life or death decisions with very little knowledge and information about the patient, their condition or their wishes (Smith et al., 2009). This is compounded by a strong theme across all the literature of confusion in roles and application of palliative care which is often at odds with the usual and more aggressive care provision in the ED (Beckstrand et al., 2008, Smith et al., 2009, Smith et al., 2010a, Gardiner et al., 2011, Grudzen et al., 2012b). This theme is addressed in more detail in later chapters as it arose throughout the study.

ED staff opinion appeared divided on the idea of having palliative care provision in the ED at all (Smith et al., 2009, Carunchio, 2011, Gardiner et al., 2011, Grudzen et al., 2011b). These data were from the US where, as stated in Chapter One, palliative medicine is now a subspecialty of emergency medicine. The literature identified resistance and confusion to this integration with some physicians asserting that such care was outside of their role and not what they had trained to do (Grudzen et al., 2011b). Even where more positive attitudes were found, the confusion remained around palliative care terminology, access to palliative care services, and roles in the provision of palliative care (Grudzen et al., 2011b, Stone et al., 2011). A common consensus for staff was that the ED was a damaging environment for such a vulnerable patient group and many felt uncomfortable with their presence. Interestingly, this attitude towards palliative care patients may have manifested unintentionally in practice, as many patients with palliative care needs, particularly older people, reported feeling a reduced sense of worth and significance in the ED (Bridges and Nugus, 2009, Gordon et al.,

2010). The impact of how staff communicated with patients and the amount of attention provided led to some patients reporting that they felt devalued and defensive about their presence in the department (Gordon et al., 2010). Given that this may have been the result of staff confusion, uncertainty or concern that such patients were in the wrong environment, this is a regretful outcome.

Attitudes to palliative care among patients and carers were also divided. Staff expressed concern in raising the topic of palliative care due to confusions over terminology and understanding which could further distress patients and carers and complicate care provision (Heaston et al., 2006, Beckstrand et al., 2008). However, patients more familiar with, or enrolled in palliative care programmes in US papers, were found to respond positively to palliative care referrals and discussions (Smith et al., 2010a). In situations where patients were unaware of this classification for their condition, palliative care was often associated with imminent death and the topic was alarming and met with resistance (Smith et al., 2010a).

### ***Training and education***

The mostly likely reason for negative reactions and experiences of palliative care for staff and, by extension patients and carers, was a lack of training and education despite the increasing incidence of older palliative care patients in the ED. The review found commonalities in experiences, attitudes and knowledge across the papers. Staff often struggled to see the death of a patient as anything other than a failure (Payne et al., 1998, Gardiner et al., 2011, Grudzen et al., 2011b), believed that the principles of palliative care were at odds with the ED philosophy (Gardiner et al., 2011); and were uncertain about how to react to and manage complex palliative care patients (Gardiner et al., 2011).

Almost all papers concluded with the assertion that more research was required into palliative care in the ED, e.g. Grudzen et al (2011b); Stone et al (2011). , and highlighted the need for tailored training and education in palliative care (Payne et al., 1998, Heaston et al., 2006, Beckstrand et al., 2008, Smith et al., 2009, Beynon et al., 2011), and the development of the ED model of care (Heaston et al., 2006). Training and education recommendations ranged from communicating with other services and integration with the palliative care teams (Stone et al., 2011), improved identification of those with palliative care needs (Couiliota et al., 2012), training into pain management and symptom control (Shearer et al., 2014),

communication (Way, 2008), bereavement support (Payne et al., 1998, Beckstrand et al., 2008), and service redesign (Heaston et al., 2006, Beynon et al., 2011).

## **2. 5 Gaps in the literature: applying the emerging themes**

As the secondary experiential literature was explored it became evident that the factors influencing palliative care encounters in the ED positively or negatively often stemmed from aspects related to knowledge, practice and attitudes. The findings from this early stage of the narrative review revealed a limited body of UK-based literature about palliative care delivery for older people in the ED, with only slightly more from overseas. The existing literature implies a lack of agreement and confusion about palliative care and the role of the ED and ED practitioner, and consensus that these factors need addressing. Communication and ED design have been reported as major barriers to the provision of palliative care, and training and education in palliative care provision are highlighted as lacking.

The issue of training and education was an important one within the narrative review and therefore needed to be retained within the exploratory work of this study. However, as a significant portion of the literature was taken from international studies, it is important to outline here what is already known about UK palliative care training.

The end of life care audit introduced in Chapter One included data from two online surveys, one with doctors and one with nurses, about end of life care (Burr, 2008). The first survey, for doctors, questioned attitudes, awareness and practice as it relates to palliative care. Over 900 doctors from a range of specialties responded, including a number of emergency care specialists. The second was for nurses and investigated views on the provision of end of life care services, training and challenges. The nurse survey was smaller with only 181 respondents, and emergency nurse respondent figures were not provided. The survey found that only 18% of nurses and 29% of doctors had received pre-registration end of life care training, and only 15% and 39% respectively had received end of life care communication skills training. The audit did not specify whether communication training was provided pre or post registration. Overall, practitioners highlighted a lack of end of life care training, but felt generally confident in recognising and delivering end of life care (Burr, 2008). Across specialties, emergency and intensive care specialists were the least confident in providing end of life care, and amongst generalist practitioners, GPs ranked their confidence lowest when it came to identifying when end of life care should start. All of these findings correlate with the findings of the narrative review. In addition GP uncertainty in initiating end of life care



practices in the community may be linked to service or communication breakdown and potentially accounts for why some palliative patients present to the ED.

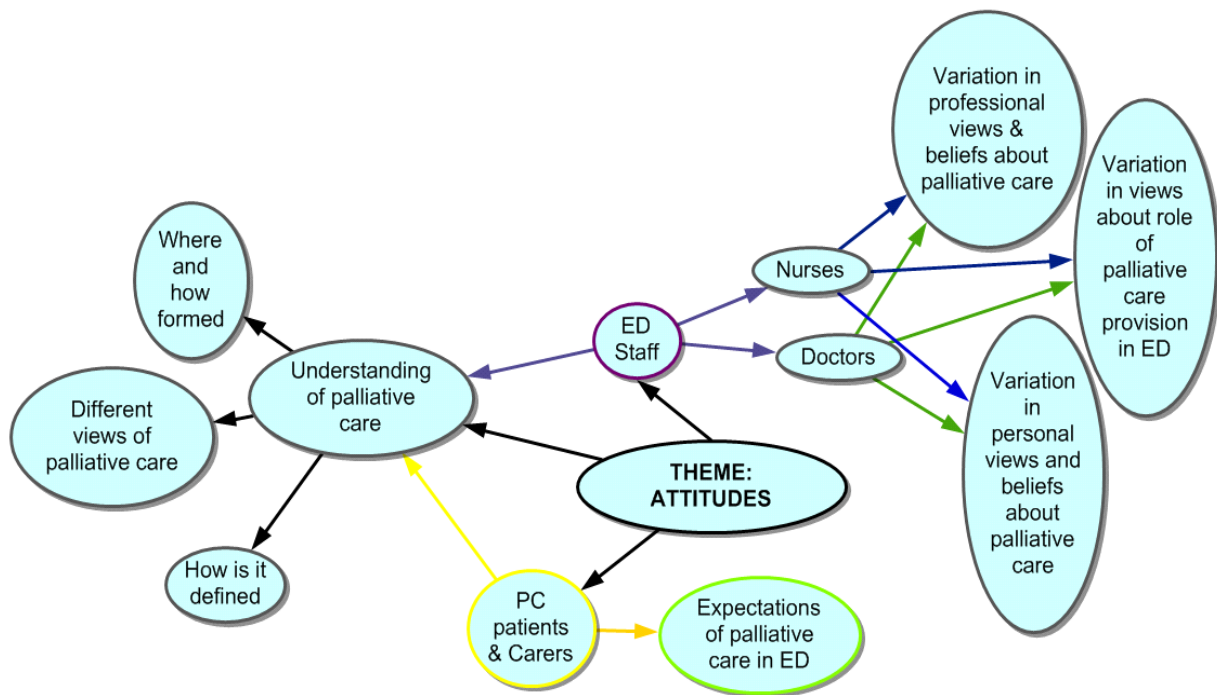
### **2.5.1 Developing a framework for conceptualising palliative care in the ED for older people**

To summarise, the narrative review conceptualised the findings within three themes: attitudes, knowledge and practice. In order to apply them to the work of this thesis a thematic framework was developed (Lathlean, 2007). Chapter Three goes on to develop this framework further, by combining the three themes and adapting them to form a conceptual framework that supported and directed the thesis methodology. Of key note in the narrative review is that rather than answering questions about how to improve experiences of palliative care in the ED, the literature has instead raised questions for the research by highlighting gaps for more detailed exploration. Figures 4, 5 and 6 present the three themes and the questions they raise.

- **Attitudes (Figure 4)**

- What are the attitudes of patients, carers and staff towards palliative care?
- Where, when and how are these attitudes formed?
- How do patients, carers and staff define palliative care?
- What do patients and carers expect of the ED and ED staff?
- What are ED staff attitudes, beliefs and understanding about palliative care?

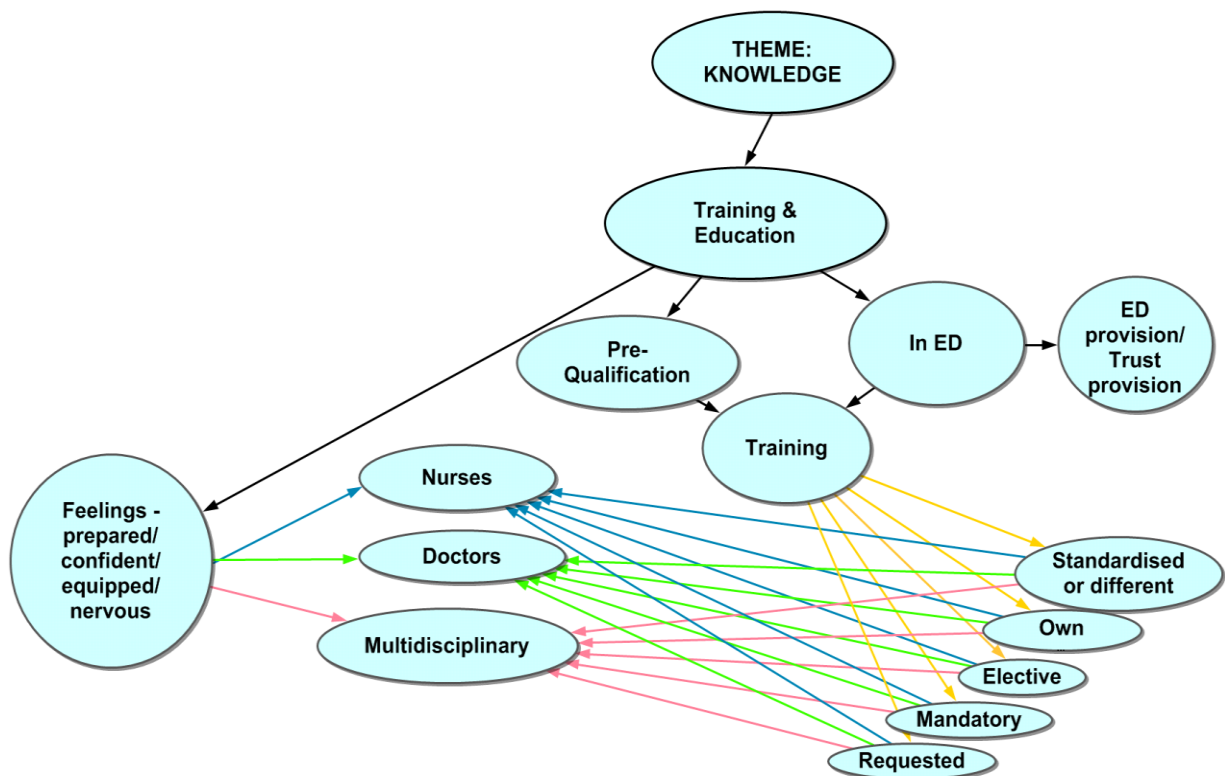
**Figure 4: Emerging theme: Attitudes**



- **Knowledge (Figure 5)**

- What palliative care training and education have ED staff had at various stages of their career including:
  - pre and post-registration
  - in the ED
  - from different jobs or as part of mandatory updates
- Do ED staff feel prepared and equipped to provide palliative care?

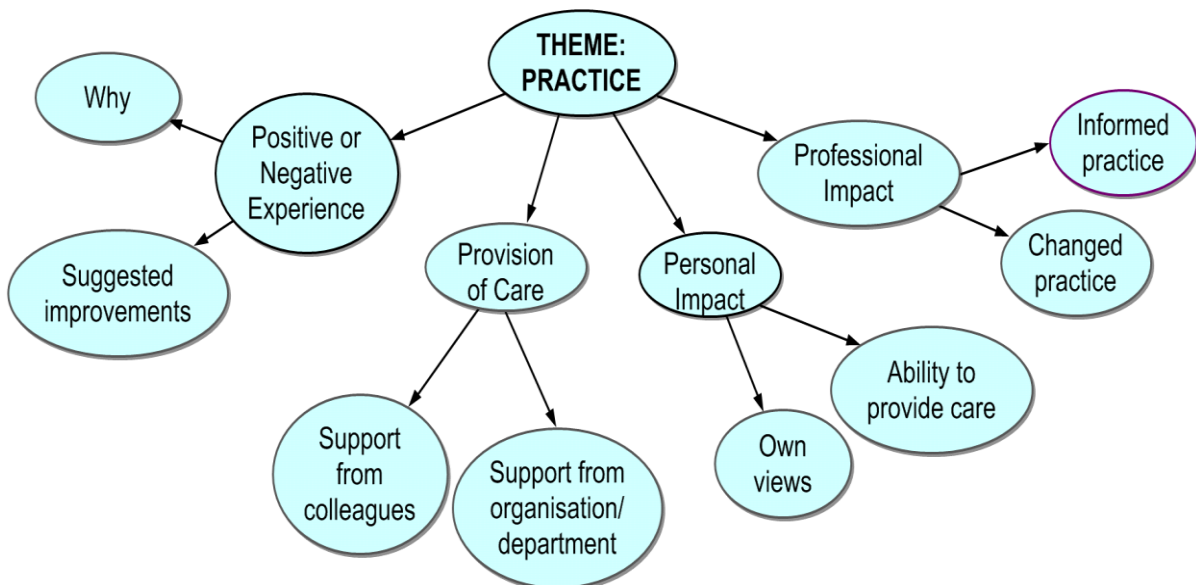
**Figure 5: Emerging theme: Knowledge**



- **Practice (Figure 6)**

- Are experiences of palliative care positive or negative for older patients, their carers and ED staff?
  - Why?
  - Do patients, carers and staff have suggestions for improvements?
- How is care provided?
  - Do ED staff feel supported by their colleagues?
  - Do ED staff feel supported by the ED and organisation they work for as a whole?
- Is there a personal impact of providing or receiving palliative care in the ED?
  - How has it impacted on personal beliefs and views?
  - Do ED staff consider their practice to have been affected by this patient group?
- Is there a professional impact of providing palliative care in the ED?
  - How, if at all, have ED staff seen and made their practice change to respond to the changing demographic and their needs?
  - How do staff ensure that their practice is evidence-based and well informed?

**Figure 6: Emerging theme: Practice**



## **2.6 Conclusions from the literature**

The findings from the narrative review that could be posed as arguments against integrating palliative care in the ED include: the busy environment (Heaston et al., 2006), the lack of privacy (Beckstrand et al., 2008), and the volume of patients with more urgent needs who are triaged ahead of palliative patients (Smith et al., 2009). However, the numbers of older palliative patients in the ED and subsequently as hospital admissions, are increasing (National Confidential Enquiry into Patient Outcome and Death, 2009). This suggests that, rather than ignore their presence, the ED could instead work alongside community and inpatient services to meet the ethical dilemmas and challenges, as patient needs must be met regardless of the environment (Tardy, 2002, Kompanje, 2010).

Although various pilot studies and redesign models have been covered briefly in Chapter One and this chapter, the majority are from overseas, particularly the US (Hwang and Morrison, 2007, Gisondi, 2009, Glajchen et al., 2011). Extrapolation and replicability of these works to the UK is challenging due to different health care systems, and training and education models (Quest et al., 2011). The narrative review has shown a gap in UK literature about knowledge of ED staff views, experiences and understanding of palliative care.

The questions raised from the early outcome of the narrative review of the literature suggested that an EBCD study aiming to improve the experiences of palliative care in the ED for older patients, their carers and staff might face certain challenges including:

- Staff awareness of older patients with palliative (not end of life) care needs in the ED.
- Agreement that research is needed to improve the experiences of patients, their carers and staff.
- Ability to identify and recruit older palliative care patients to the study.

Chapter Three discusses the research methodology used for the study. The subsequent decisions for how the study responded to the challenges above are presented in the following chapters, as they were dealt with chronologically.

## **2.7 Critical reflection**

Organising, managing and understanding the literature for this thesis was an on-going and challenging process. The previous chapter outlined the social and political changes at the start of the thesis, and this chapter demonstrates the paucity of evidence-based, academic and empirical literature available at that time. The decision to undertake an iterative narrative

approach was a pragmatic one, as this provided a logical route for exploring all available and pertinent literature, regardless of design and quality.

The findings from the limited literature were interesting. The review highlights the lack of UK based literature, particularly in relation to patient experiences, which suggested that it might be challenging to recruit them to this study. Another interesting finding was the advanced development of palliative care in the ED in the US compared to the UK, which later led to an expansion of this research (Chapter Five).

This thesis shares an honest and chronological process and, reflecting critically on the decisions made in the early stages of the review, I regret not expanding the narrative earlier to include end of life care literature. Although this did not impact negatively upon the conduct of the study and the search was later updated to include these papers, I had a lack of awareness of the perspectives of staff on end of life care as I began this research. The subsequent misinterpretation between the ED staff and me regarding the patient group to be recruited to the study is dealt with more fully in Chapter Four. I was focusing on palliative care patients who were not yet in the last six months of life. For ED staff however, their limited time frame with patients and the tight window of care meant that they could not always cater to the full trajectory of conditions, but instead had to focus on the immediate problem in front of them. In palliative care this has historically been the end of life, at the terminal phase. Inclusion of end of life care literature earlier in the review process would have helped me to understand this perspective more quickly.

Despite this, the findings helped give the study an early frame and direction for staff enquiry. I had been uncertain what quality and quantity of literature I would find. The questions raised by the search results made me feel uncertain quite how to commence with a service improvement study when it was not certain what aspects of care required improvement, or what UK older palliative care patients and their carers would want. The review impacted on how the study progressed and this is discussed in the next chapter. At this stage it was not certain if a full EBCD project would actually be possible, or if it would be reduced to a purely exploratory study into experiences alone.

## **2.8 Conclusion**

In these first two chapters the narrative has set the scene and context for this thesis. Unmet patient care needs have been demonstrated, and confusion and gaps in literature and practice highlighted as evidence for the need to undertake this research exploring and improving palliative care in the ED for older people, their carers and staff. The narrative now moves on to tell the story of how this study sought to improve experiences of palliative care in the ED with older patients, carers and staff. It continues in Chapter Three with a critique of the methodology underpinning the research.

## **CHAPTER THREE: PREPARING TO FIND THE STORY**

### **(Methodology and methods)**

#### **3.1 Introduction**

In the previous chapters reference was made to new innovations responding to the changing needs of older palliative care patients, from community settings in the UK (Department of Health, 2006, Pellett, 2009, Leadership Alliance for the Care of Dying People, 2014a), and within the ED in the US (O'Mahony et al, 2008, Grudzen et al., 2011a, O'Mahony et al, 2013). However, reference was made to each of these innovations regarding the apparent lack of patient and public involvement, despite increased encouragement from various groups (Involve, 2012a, Foot et al., 2014).

#### **3.2 Chapter overview**

This chapter deals with the methodology identified to bridge the gap between new service innovations and patient, carer and healthcare professional participation, namely: Experience-based Co-design (EBCD). EBCD, appraised in more detail below, offers a practical and rigorous process for exploring and improving upon palliative care experiences in the ED, with full involvement from those providing and using the service. Before the appraisal of EBCD, it is helpful to explore further the epistemological and ontological approaches in the redesign efforts presented in the previous chapters, as these philosophical and theoretical perspectives demonstrate the rationale for selecting this methodology more fully.

#### **3.3 Epistemology, ontology and changing paradigms**

There is a changing healthcare design services paradigm, which challenges the medical epistemological status quo of re-design processes (Glasby and Beresford, 2006). The medical paradigm, in which healthcare professionals exert a heavily paternal influence on patient experience and care with a tokenistic nod to 'involvement', is slowly being replaced by one that seeks fully to incorporate the insight of the 'expert patient' (Shaw and Baker, 2004, Involve, 2012a). This is discussed in more detail in Chapters Six and Seven. Subsequently there has been a growing demand for patient and public involvement in all processes and at all levels of healthcare, health research and health services design, by government, funder and public organisations (Involve, 2012a, Foot et al., 2014, Leadership Alliance for the Care of Dying People, 2014a). Recent evidence has shown that re-design and research efforts which



include user groups are likely to have positive outcomes for those involved and the services in question (Foot et al., 2014). However, this is not overtly obvious in the current epistemology underpinning the development of palliative care initiatives in the ED, which are predominantly medical in their focus; for example, innovations that support the practitioner and wider system but do not directly include or take into account the patient/carer perspective (Quest et al., 2011, Martin-Khan et al., 2013).

These innovations are breaking new ground in terms of service re-design, but there is little evidence available to demonstrate patient or public involvement (O'Mahony et al, 2008, Quest et al., 2011). The challenges in identifying the best methods for palliative care provision in the ED are not insignificant, particularly given how relatively new this field is, and how emotive and poignant end of life experiences are for all involved. Thus the absence of representation from patient and public forums in planning and design activities suggests that there may be gaps in the final decisions and processes that these groups could positively impact upon.

An attempt was made recently to respond to the challenging questions around development of palliative care in the ED by the American College of Emergency Physicians. It convened a conference aiming to develop new research agendas in five areas, one of which was end of life care. A Palliative Care Workgroup, comprising a mixed team of emergency, geriatrics and palliative medicine clinicians, policy makers, insurers and researchers, explored this area (Quest et al., 2011). However, the workgroup did not include any of the actual population under discussion, despite their personal and unique experience of using the ED for palliative care needs.

The Workgroup's subsequent publication sets out five research priorities for palliative and end-of-life care in the ED, with a focus on older people (Quest et al., 2011) (discussed below). However, these research priorities demonstrate a medically focused epistemology among the workgroup, being largely clinical and lacking integration of patient or carer input in any planning processes except in assessing the effectiveness of interventions. Despite the lack of patient and public involvement, the resonance of globally shared ED-based palliative care needs (highlighted in Chapter One) means that consideration of the research priorities is still an important activity for the UK (Marie Curie, 2015). In addition UK EDs are some way from tackling this healthcare challenge at such a multidisciplinary level.

The Workgroup's five research priorities for palliative care within the ED are summarised below:

- 'Descriptive' – to correctly identify palliative patients within the ED;
- 'Attitudinal' – to explore staff perceptions and understanding of palliative care delivery to patients in the ED;
- 'Screening' – to identify the most pertinent assessment tools;
- 'Outcomes' – to monitor how effective care and interventions are for patients;
- 'Resource allocation' – to review and assess service provision and transitions in and out and of the ED; and
- 'Education of clinicians' – to establish core competencies for ED staff and assess interventions (Quest et al., 2011).

As it transpired, all five of these areas emerged within the current study through data collection and analysis from staff and patient interviews, focus groups and subsequent selection of improvement priorities, and are explored further later in the thesis.

It is not simply the prevailing medical epistemological stance that this thesis questions by its use of EBCD; it also probes the ontology that supports this epistemology. Despite the arguments and evidence presented which support patient and public involvement in healthcare redesign efforts, this chapter has shown that not all healthcare providers automatically think to include them in this way. For it to become normal practice, an ontological shift needs to occur in which healthcare providers recognise the limitations of their own understanding of 'what is best for this person', and accept the value that patient experience and knowledge can bring (Black, 2008, Foot et al., 2014). This is particularly the case in palliative care efforts, where it is vital that there are relationships built on trust and recognition of what matters most to the person who is dying (Black, 2008). Palliative care is concerned with recognising the value and worth of the individual and those closest to them, working in partnership to set goals of care (Marie Curie, 2015). Palliative care research, in any setting, but particularly one as unstable as the ED, needs to maintain this focus.

### **3.4 Selection of study methodology**

In the early stages of development of this project, the lack of previous research including palliative care patients, carers and ED staff suggested that a phenomenological methodology might be suitable. This would generate foundational material exploring and describing lived

experiences (Green and Thorogood, 2009). However, the apparent contradiction of a palliative patient purposefully going to an environment that is known to be loud, disruptive and frightening for many people led to consideration of an ethnographic approach (Green and Thorogood, 2009). This direction could help to identify what was triggering such visits and to better understand how ED staff responded to an atypical patient group. While a phenomenological or ethnographic approach would have provided new knowledge, this thesis is based on a moving infrastructure of care within the NHS and a changing demographic with complex conditions. It would have been fascinating to produce a commentary on this trend, but it was apparent that neither methodology was the most useful for this study. Instead, the lack of clear parameters or guidelines for the ED to act upon, combined with the absence of patient and carer input suggested a participatory action-based research approach might produce something more constructive to offer back into clinical practice.

Due to its complexity and wide application there is no single agreed definition of AR, (Zuber-Skerritt and Fletcher, 2007), but social scientists posit that quality AR studies are identified, characterised and understood through their participatory epistemology and ontology (Zuber-Skerritt and Fletcher, 2007). The initial appeal of AR, which includes Participatory Action Research (PAR), stemmed from consideration of its epistemology. The AR epistemology sits within an interpretative-constructivist paradigm (Green and Thorogood, 2009), using collaborative processes to *'...improve learning in order to improve social practices...'* (Hockley et al., 2013a, p.9). Put another way, AR, often used within complex health services, is recognised as *'...one way of conducting research within a learning organisation that can benefit both the organisation and the body of knowledge about which a thesis is written...'* (Zuber-Skerritt and Perry, 2002, p.173).

Given the unique nature of the research problem under investigation (palliative care for older people in the ED), the flexibility and application of AR to a diverse range of environments, situations and organisations was a key factor. Indeed, a growing movement of palliative care researchers advocate this approach as an important method for challenging assumptions of care needs (Hockley et al., 2013a). The challenge is implicit in the ontological perspective of AR which safeguards and values the views and experiences of those involved as equal co-collaborators; in this case, older palliative patients, their carers and ED staff (Hockley et al., 2013a). Put simply, by extending the boundaries of redesign research in healthcare to those who are involved in providing and using a service, they are enabled to question and generate new knowledge about their experiences. The new knowledge which emerges from multiple

perspectives is then considered collaboratively, using problem-posing and solving within shared situations, rather than the traditional research approach of being ‘done to’ by external facilitators (Green and Thorogood, 2009, Smith et al., 2010b).

### **3.5 A critical appraisal of Action Research**

As with any research approach there are criticisms and disadvantages to AR, particularly when undertaken as part of a doctoral thesis. Before commencing the study, a sound understanding of these factors was needed, along with the response from experts within the field. The first criticism deals with the management and balance of the apparent dichotomy contained within the name, ‘action’ and ‘research’. Critics argue that a tight focus on one aspect of practice and the priorities of those in that area (the action), jeopardises the contribution of the work to wider practice and the theoretical knowledgebase (the research) (Green and Thorogood, 2009, Froggatt, 2013). Others go further, challenging the legitimacy of calling AR a research design rather than a model for service improvement and development (Green and Thorogood, 2009). The flexibility required for the conduct of AR projects has led to contention among more traditional positivist researchers who regard the AR approach as ‘...*sloppy and lacking in rigour...*’ (Fisher and Phelps, 2006, p.158).

Leading AR scientists acknowledge these factors, as well as citing other challenges such as potential vulnerability of participants; sustaining and measuring change efforts, reliance on collaboration and balancing power relationships; including the potential for the process and feedback to be threatening to those involved (Meyer, 2007, Smith et al., 2010b). Undertaking AR as part of a doctoral study contains an additional challenge in the move away from a conventional methodology as other academics may be unaware, unfamiliar or hostile to the approach (Zuber-Skerritt and Fletcher, 2007). Despite these critiques, there are strong arguments that AR is a more fitting approach than traditional research in eliciting change and improving practice and organisational learning (Zuber-Skerritt and Perry, 2002, Meyer, 2007).

To support those involved in AR studies and answer critics of the approach, proponents of the methodology have outlined a number of traits that one would expect to see in a high quality AR project. Although often framed in different ways, at their essence the traits are:

- the generation of new understanding and knowledge;
- closure of the knowledge gap on a given topic between a small group of scientists and the wider society;
- practice-orientation and change in the phenomena under investigation;
- rigour in the study conduct;
- making one's own thoughts and views explicit while acknowledging and using different worldviews;
- making results public to establish accountability, and
- ethical conduct (Meyer, 2007, Zuber-Skerritt and Fletcher, 2007, Green and Thorogood, 2009).

Maintaining the balance between action and research is addressed by making both priorities transparent from the outset and following them through the project (Green and Thorogood, 2009). Of course, due to its very nature, AR efforts may still sometimes develop in unexpected directions. To this end, questions of rigour, predominantly from those who follow a positivist paradigm, are answered in the cycles of critical and self-critical reflection and evaluation, and the transparency of a clear and meticulous audit trail demonstrating the decision making process at each stage (Zuber-Skerritt and Fletcher, 2007, Green and Thorogood, 2009, Hockley et al., 2013a).

Given its opposing epistemological and ontological stance to positivist paradigms, one suggestion for the appraisal of an AR study is to focus less on traditional lines of rigour per se, and more on the researcher and their values (Froggatt, 2013). To this end the demonstration and assessment of 'quality' becomes the key marker of AR endeavours (Froggatt, 2013) and is a shared role for the researcher and the reviewer. Again, AR scientists present quality indicators in different terms, but at their core they pursue the same criteria:

- democratic involvement and empowerment of participants;
- rigorously monitored practices and outcomes;
- demonstration of different forms of knowledge drawn on in the study;
- evidence of critical and self-critical reflection upon the value of the work, processes and participants;
- generation of new knowledge, and
- the dissemination and potential for application of findings to a wider body of knowledge (Meyer, 2007, Zuber-Skerritt and Fletcher, 2007, Froggatt, 2013).

The challenge of implementing and sustaining change efforts is acknowledged and answered in the reflection of the valuable learning that can emerge from such efforts, while emphasising that change takes time and is by its very nature, a fluid process (Meyer, 2007).

The choice of AR for this thesis was compelling as its flexibility caters to projects with unknown or changing perimeters, in this case an area of limited existing knowledge, involving vulnerable participants with unknown opinions, and set in a busy and demanding environment. Working alongside older palliative patients, their carers and ED staff raises a number of ethical issues such as gate keeping, recruitment and consent processes, potential patient deterioration, and distress during research activities that explore sensitive issues (Goodman et al., 2012). The specific ethical considerations are explored further below and in Chapters Four to Seven according to their impact and management within the research story.

The heightened vulnerability of the participant group within this thesis aside, a challenge for all AR projects is the vulnerability of its participants in the conduct of the study, and the need for ethical practice as an intrinsic part of quality research in general. Here again, a set of principles have been developed to help support and ensure consistency in conduct and values within AR. The principles include:

- documentation of all discussions procedures or joint decision making;
- transparency and visibility of all stages of the project to all participants;
- collaborative validation and authorisation of findings;
- confidentiality agreements;
- study withdrawal rights for participants;
- pre-agreed disagreement management plans;
- permission for future use of findings, and
- statements regarding procedural principles (Meyer, 2007).

Of course, while sets of principles that grant each participant and collaborator an equal and valued voice sounds ideal, the reality and imbedding of such principles can be met with unexpected difficulties. Challenges, particularly around conducting an AR study in hierarchical organisations such as the NHS, have been documented (Munn-Giddings et al., 2005, Smith et al., 2010b). External AR scientists entering such an institution may be faced with distrust, concerns over who is in charge and a lack of ownership (Munn-Giddings et al., 2005, Smith et al., 2010b). Applying the principles then takes on a very practical role,

drawing collaborators into discussion to determine, identify and resolve root concerns (Smith et al., 2010b). Inherent in such an open and inclusive methodology are human factors that can take time and skill to respond to. Application of the principles to the challenges in this project is documented according to the chronological undertaking below, and in Chapters Four to Seven.

The exploration of AR for the conduct of this study included consideration of the three different types:

- Technical-scientific and positivist action research,
- Critical and emancipatory action research, and
- Mutual-collaborative and interpretivist action research (Meyer, 2007).

It is the latter of these three that best fitted the investigative aims of the project.

The first, technical-scientific and positivist action research, was rejected as it sees the action researcher as the expert and uses traditional scientific methods to test types of interventions, thus missing the value and expertise not only of the palliative patient and carer, but also of the ED staff who are working in the environment.

The second, critical and emancipatory action research was considered too politically focused. There was a risk that the study would become an exploration of the power roles of palliative patients, their carers and staff and lose its focus on the research goal of learning from their experiences in order to improve palliative care in the ED. However, this could be a valuable study given the current political climate and debates surrounding the NHS and ED introduced in Chapter One.

The third type of AR, mutual-collaborative and interpretivist action research, resonated with the ethos of the study, as it embraces partnership between members of different groups to explore and identify solutions to challenging situations. It was while considering this form of AR, also known as Participatory Action Research (PAR), that Experience-based Co-design was identified. EBCD is drawn from PAR and enhanced by other influences. Where PAR provides a philosophical approach and quality principles on which to ground the thesis, EBCD provides a replicable process and toolkit for conducting the study (The King's Fund, 2011).

EBCD, critiqued below, incorporates a structure with various methods, including interviews and focus groups, to elicit the required knowledge which contains the triggers for change. It then draws participants together to design out negative aspects of the situation under investigation and enhance positive ones. Within EBCD there is a deeper philosophy which places an emphasis on experience as the leading force within the research process (Robert, 2013). The practical response to the theoretical considerations of patient, carer and ED staff experiences of palliative care in the ED meant that EBCD seamlessly lent itself to the study, while simultaneously providing the flexible but structured framework required for quality AR studies (Froggatt, 2013).

### **3.6 Experience-based Co-design**

Experience-based Co-design (EBCD) is defined as ‘...*an approach that enables staff and patients (or other service users) to co-design services and/or care pathways, together in partnership...*’ (The King's Fund, 2011). Originally called ‘Experience Based Design’, the title changed to ‘Experience-based Co-design’ to ensure that the necessary emphasis was placed on the collaborative and equal role of all participants (Donetto et al., 2014).

Use of EBCD in healthcare is growing (Bate, 2007) with increasing endorsement of the approach. The King’s Fund refer to it as a ‘...*powerful and effective way of improving patients’ experiences of services.*’ (The King's Fund, 2011). A practical toolkit has been developed to support EBCD studies in the NHS (The King's Fund, 2011). While its epistemological and ontological roots stem from the PAR paradigm, EBCD stands as a methodology in its own right. This is due to its comprehensive design and methods, and its experiential co-design philosophy which pulls from three other bodies of knowledge: narrative-based approaches to change, learning theory and user-centred design (Bate and Robert, 2007), outlined below. The ethos of the approach is an anthropological one, where the aim quite simply is to ‘...*capture, understand and then improve how patients actually feel about and experience a health care process or service...*’ (Robert, 2013, p.138).

A narrative-based approach in research is one that values the power of storytelling. Within EBCD it is seen as the very foundation of experience-based design (Bate and Robert, 2007). Narratives are viewed as an effective method of capturing not only the experience, but also the *meaning* of that experience as understood by the storyteller (Bate and Robert, 2007). Although this is highly subjective, it is the subjectivity that is most valuable in the EBCD process. The words and tone used to describe an experience, and the detail included or



excluded reveal, what is most important to the narrator. Within service improvement processes, this is the fine detail that leads to identifying and understanding the perceptions, expectations, successes and failures of the existing system. But, as Bate and Robert (2007) demonstrate in their explanation of the role of narratives in EBCD, the informal nature of storytelling has a further benefit within the co-design activities, particularly in healthcare (Bate and Robert, 2007).

Service improvement work in the NHS can often be a jargon-heavy process, whereby terminology can be unclear to members of the public. This can have an alienating effect on those coming into the system who have valuable information and perspectives to share but may be inhibited or intimidated by its lack of coherence and clarity (Turner and Beresford, 2005). EBCD research has demonstrated an opposite effect whereby storytelling stimulates design processes, drawing the listener first into the narrative and then drawing out the listener's own experiences (Wolstenholme et al., 2010). Storytelling acts as an equaliser between staff, patients and carers alike, which is particularly important given the power balance required within PAR studies; it is also a means of valuing and supporting the vulnerable groups in this project.

Learning theory, a sister process to narrative-based change, is a method that allows otherwise random events in life to be understood and to become 'experience', something tangible that can be learned from (Bate, 2007). Underpinning learning theory in the context of experience is the belief that through 'retrospective sense-making' past experiences can and should be used to help understand and shape future ones (Bate, 2007). EBCD takes this learning one stage further by presenting the emerging understanding as a tool for change, not simply an accumulation of wisdom. Further, through co-design efforts, this knowledge can be passed on to others. The specific processes by which this is done in EBCD are discussed later in this chapter, and demonstrated in action in Chapters Seven and Eight.

EBCD's emphasis on being led by the needs of a person or persons who directly experience, use or are impacted by a given phenomenon, stems from user-centred design. This methodology is concerned with the output of a project, and has historically been used in product innovation (Bate and Robert, 2007) by '*focussing on usability throughout the entire development process and further throughout the system life cycle*' pg. (Gulliksen et al., 2003, p.401). The underpinning concept for this approach sits in the acknowledgement that consumers are more likely to know what they want from a product than the manufacturer.

Rather than guessing or conducting market research, manufacturers invite users in to help lead the design process (Bate, 2007).

The adoption of user-centred design into service improvement and innovation within the NHS is relatively recent. An evaluation was undertaken into one form of this user-controlled research in which the user groups led on all aspects of the work. It found that, although not without challenges (such as resource implications, user support, training, disputes over terminology and definitions), user involvement could elicit a sense of control, empowerment, emancipation, participation, equality and antidiscrimination (Turner and Beresford, 2005). This approach has been widely adopted and has many advocates (Department of Health, 2012, Patients and Information Directorate, 2013). The involvement of participants in this research study is explored in more depth in Chapters Six and Seven together with a critique of the wider challenges faced.

EBCD draws from the three bodies of knowledge presented; narrative-based approaches to change, learning theory and user-centred design, but also ties them together while keeping the experiences of individuals who are most affected by a healthcare process or service at its core. The individuals involved act as the main drivers for change and the project retains a user-centred design approach throughout, as it is their lived experience, their expertise and their knowledge of what needs improvement that underpins and propels the entire work. The actual process (described below) enables participants to share and explore their individual experiences of a service retrospectively, equipping them to draw meaning and understanding from their story in order then to find the shared narrative. The shared narrative is used as a foundation to move the process beyond the original experience, and onto the unique element of EBCD: healthcare staff, patients and carers working as co-designers to develop priorities and strategies to improve future experiences. This mechanism, which for many participants can be as powerful as the subsequent service changes (Tsianakas et al., 2012), allows patients and carers to work as equals *with* staff as ‘user designers’, rather than simply sharing their experiences and being ‘responded to’ (Bate, 2007). While the foundation of this methodology is not entirely innovative, the combination of approaches has generated a practical and inclusive change exercise and can be a valuable way of improving practice (Robert et al., 2015). The participants (in the case of this thesis, older palliative patients, their carers and staff) ultimately form a cohesive team, united by the mutual goal of improving their shared experience.

In practice EBCD follows a relatively simple cyclical systematic process of exploration, knowledge construction and action. This is done in the following six stages (Robert, 2013):

**Stage 1: Setting up the project:** This stage deals with project management, for example gaining ethical approvals and access to gatekeepers for recruitment of staff and patient/carer participants.

**Stage 2: Gathering staff experiences:** Approximately 12 to 15 staff from all grades and roles are interviewed about their experience of working within the service. Interviews are semi-structured and audio recorded, then transcribed and analysed thematically. Non-participant observation of the service may also occur to give context and perspective.

**Stage 3: Gathering patient and carer experiences:** This stage runs in parallel to Stage 2. Recruited via agreed gatekeeping processes at the service, 10 to 12 patients and carers take part in individual, unstructured, narrative-based, filmed interviews in which they describe their experience and journey through the system or service. A copy of their own film is given to them to view and participants are asked for their permission to use the film and for it to be shared with other patients, carers and staff. The films are analysed thematically looking for ‘touch points’; the definitive moments that make or break an experience (Bate, 2007). A 35-minute film is created compiling footage from the interviews that best demonstrates the touch points. Patient and carer participants attend a viewing of the film, and a discussion is facilitated on the reactions, comments and possible changes they feel are needed. A mapping exercise is then undertaken during which participants consider the emotional impact of the touch points. To conclude the patient and carer session, the participants vote on and agree their shared priorities for service improvement.

**Stage 4: Bringing staff, patients and carers together in the first co-design event:** All participants are invited to a joint event. The film is shown and the staff findings are shared. Participants then volunteer to join mixed discussion and planning groups to identify joint service improvement priorities.

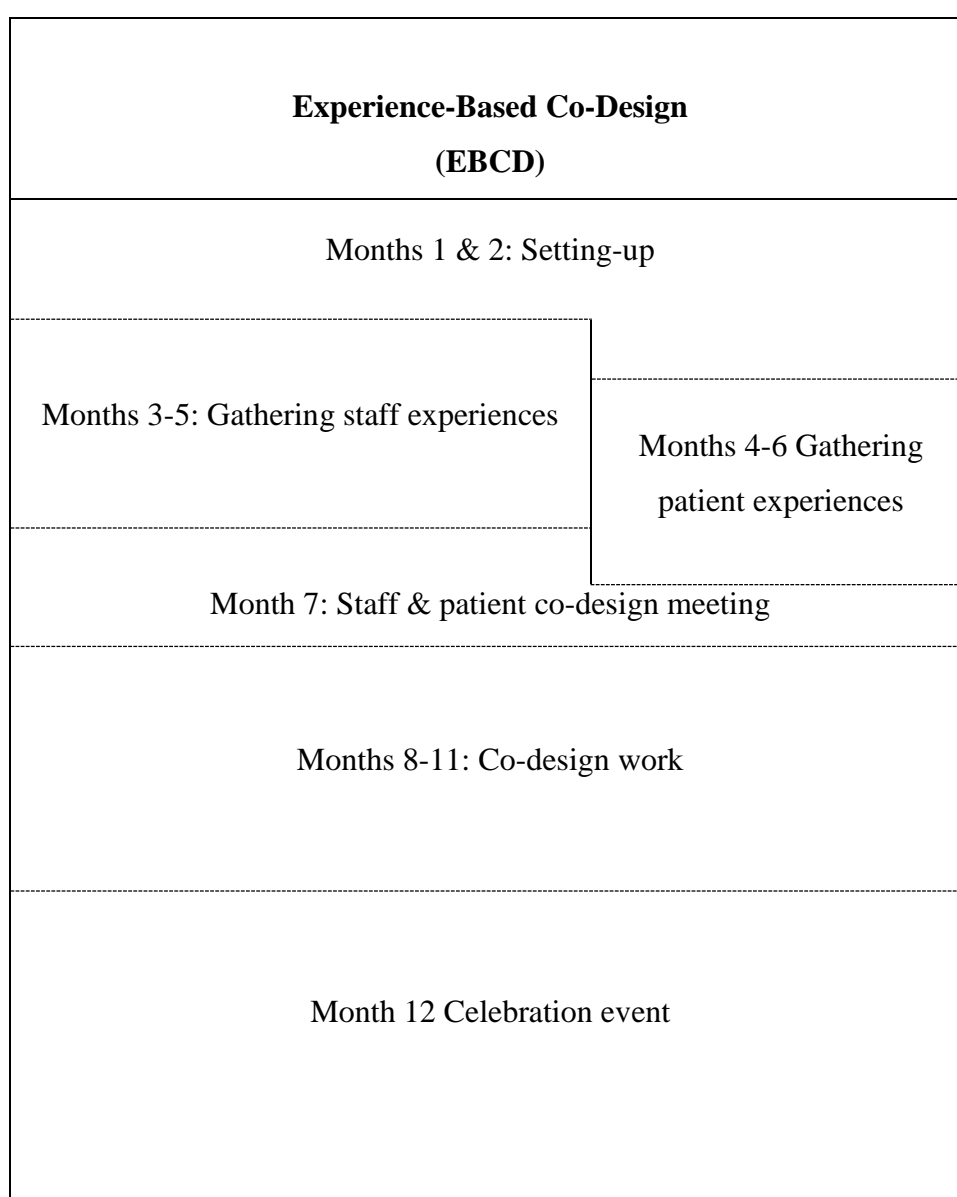
**Stage 5: Ongoing co-design work in small groups:** Mixed groups of about four to six healthcare staff, patients and carers from Stage 4 work together over about three

months. Each group selects and works on developing and implementing a specific improvement priority.

**Stage 6: A celebration and review event:** All participants come together to celebrate and discuss their progress. The event is also used to plan the next stages of the improvement work.

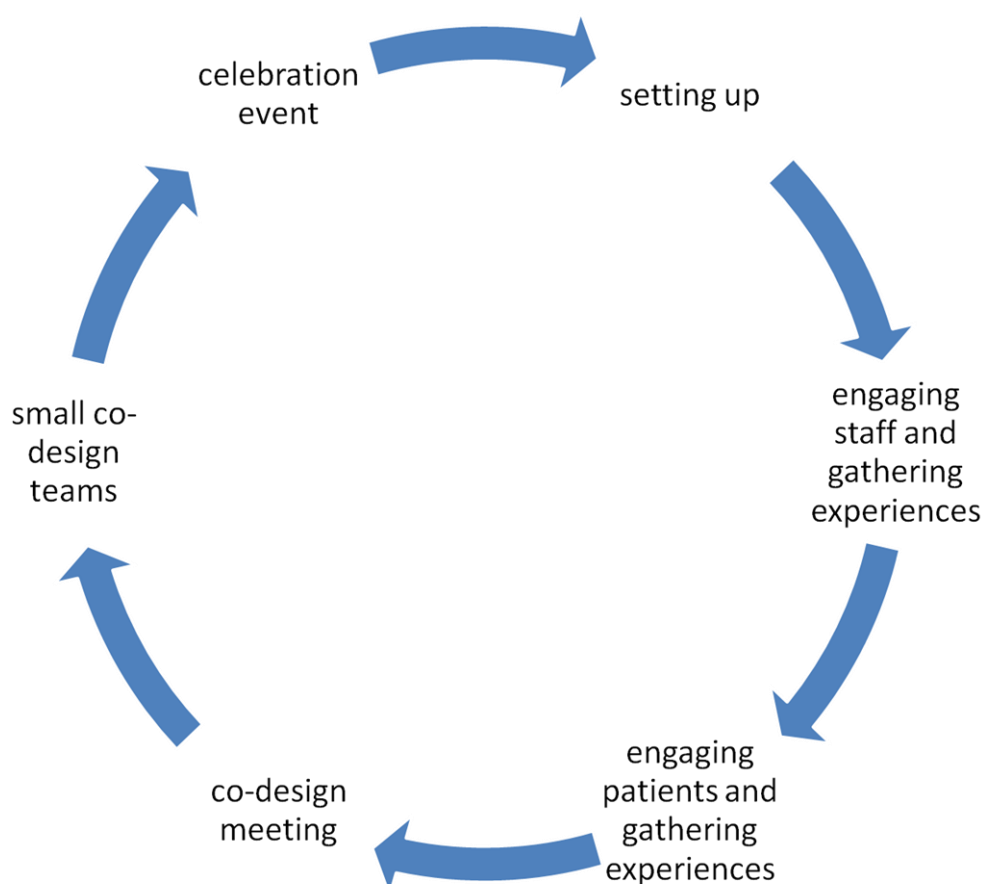
The expected duration of the stages and cyclical nature of EBCD are depicted in the visual representations below (Figure 7 and 8).

**Figure 7: Timetable of EBCD stages**



‘Timetable of EBCD’ (Locock et al., 2014, p.16)

**Figure 8: Cyclical nature of EBCD process**



**‘The Experience-based Co-design cycle’ (Donetto et al., 2014, p.12)**

### **3.7 Critical appraisal of EBCD**

As with AR, a critical understanding of EBCD was required to prepare for the practical undertaking of the study. Strengths, weaknesses, challenges, criticisms and subsequent recommendations identified by other EBCD projects were considered iteratively throughout the thesis as they became available. One particularly noteworthy publication was a report produced by leading EBCD researchers at King’s College London (Donetto et al., 2014). Using an extensive survey and interviews relating to EBCD project undertaken over the past ten years from its first healthcare study into head and neck cancer services in 2006 (Bate, 2007), the report aimed to identify: common strengths and weaknesses of EBCD; adaptations of the design; the contribution of the King’s Fund Toolkit to implementing the approach; and recommendations for future tailoring and strengthening of its application (Donetto et al., 2014). However, as with the majority of EBCD publications, the report was published in the later stages of the current study, meaning that it served more as a tool for critical reflection

than a guide for developing the research. The challenges raised by other EBCD studies are discussed below following consideration of the criticisms levelled at the methodological approach.

The methodological criticisms and responses to AR presented earlier in the chapter also apply to EBCD. However, critical researchers also dismiss AR due to the degree of researcher involvement and interaction with participants, claiming the approach is inherently biased and unempirical in nature (Kindon et al., 2010). They go on to express doubts over the legitimacy of outcomes which cannot be validated due to the individual and subjective nature of participant experience (Kindon et al., 2010). Such criticisms stem from an objectivist perspective which fails to appreciate that by its very nature, AR, and therefore also EBCD, is a flexible research approach that does not support the perception of a single reality or paradigm in which objectivity equates to evidence (Glasby and Beresford, 2006). In EBCD the 'co' refers to patients and staff, carers and facilitators, rather than to a single group and a researcher. As with AR, the researcher/facilitator is inherently involved and holds an influence; especially where the EBCD researcher is also part of the group or environment they are working within. However, to address balances of power some EBCD projects have used external facilitators who are skilled in bringing about organisational and behavioural change in relevant settings (Piper et al., 2010a, Donetto et al., 2014).

### **3.8 Strengths and weakness of EBCD**

The EBCD approach has been used in at least fifty-nine health service projects in six countries across a variety of clinical settings including: cancer; emergency services; palliative care; gerontology; orthopaedics; mental health; diabetes; drug and alcohol services; genetics; neonatal and paediatric care; haematology and surgical units (Iedema et al., 2010, The King's Fund, 2011, Boyd et al., 2012, Tsianakas et al., 2012, Bowen et al., 2013, Donetto et al., 2014). Although experience of using the methodology has been mixed, reports of strengths and weakness predominantly relate to the same factors, all of which have implications for this thesis and are considered later in the chapter. Challenges were principally concerned with: engagement and expectations of patients and staff; time management; evaluating impact and the complexity of the approach (Donetto et al., 2014).

Engagement of staff and patients early on and throughout a project was seen as a marker of success (Piper et al., 2010b, Boyd et al., 2012) but there were challenges where staff were sceptical or unclear about the process, or uncertain of the expectations of their role within it

(Donetto et al., 2014). Being offered the choice to take part rather than being forced as part of a mandatory activity was a useful strategy for building staff ownership and participation (Bowen et al., 2013). For patient/carer participants, trust in the staff and the process was key to their engagement (Tsianakas et al., 2012). However, even once engaged some struggled to see themselves as co-creators of change. Rather they felt that they were informing re-design efforts, but not ‘doing’ them (Bowen et al., 2013). One study aiming to improve outpatient services for older people recommended using ‘participatory creative activities’, activities that draw on tools, props, scenarios and testing to help participants engage and take ownership of designs (Bowen et al., 2013).

These issues of project ownership and management of relationships are present in any study involving human participants, but are magnified when working with insider/outsider roles in a historically hierarchical organisation (Mcintyre, 2008, Smith et al., 2010b). Management and ownership challenges extend to any external or academic researchers/facilitators although, as previously stated, they can also exert a positive balance to collaborative activities, such as selection of improvement priorities (Iedema et al., 2010). Recommendations for establishing and maintaining engagement through what can be a long and demanding process (Bowen et al., 2013) chiefly centre around clear communication and iterative implementation of improvements as part of the research process (Tsianakas et al., 2012). In one London-based cancer centre, the ongoing improvements that occurred almost organically cemented a ‘connection’ between patients and staff that helped establish a commitment to the work (Tsianakas et al., 2012). However, this was dependent on support from those in positions of leadership who could approve and push agendas for change (Boyd et al., 2012). Without this support, or where staff and patients were not fully engaged, the experience could be quite disheartening (Adams et al., 2013).

EBCD requires those involved to openly share their stories, positive or negative, and to listen to others without fear of reprisal or judgement. In busy environments, or with particularly unwell patient groups, finding time and appropriate environments to build trust-based relationships and to explore and improve the emerging complex issues can be viewed as challenging or unrealistic (Iedema, 2010, Adams et al., 2013). Even where this occurs, as researchers from an Australian EBCD project redesigning three Emergency Department sites across New South Wales pointed out, agreement of co-design priorities and implementation is not a certainty (Iedema et al., 2010). Therefore engagement and ownership activities also need to consider participant expectations for the outcomes of the project.

Adams et al (2013) found that, among staff, those in senior roles were more hopeful and optimistic about improvements and were able to see a bigger, longer term strategy; junior staff felt that such an intensive process needed to have significant and easily identifiable outcomes. Project outcome expectations of staff and patients were related to the physical environment, service innovations or patient empowerment and collaborative working (Adams et al., 2013). Thus the previously mentioned need for clear goals and aims early on in the project, communicated to and by all participants, is important to avoid fostering false hopes and expectations.

Practical challenges to EBCD were also identified; most significantly the creation of a patient-carer film which was found to be a time and resource-intense activity (Donetto et al., 2014), although those who had used filmed interviews found the resulting film viewing to be an effective part of the study process (Donetto et al., 2014). An accelerated version of EBCD (AEBCD) was developed to provide a more cost and time effective method. AEBCD uses pre-made patient/carers films looking at specific health conditions which are taken from the online archive 'Healthtalkonline' (Dipex, 2015). An evaluation of AEBCD found that this approach was as effective in triggering discussions in the co-design event as the traditional approach; it was quicker to evaluate, and could save up to 40% of the cost of a normal EBCD project (Locock et al., 2014). However, AEBCD does rely on there being a relevant existing film. The time factor required at each stage, as well as the overall process, is an important consideration. A time management recommendation is for the hosting organisation to view EBCD projects as a separate entity and not as an activity that can be conducted as part of day to day practice, particularly where lone researchers carry the bulk of the project (Donetto et al., 2014).

Acknowledging these challenges and designing strategies that facilitate ownership, build trust and cater for time and resource implications is a complex process, and a number of studies choose to adapt the approach (Donetto et al., 2014). While the core elements of Stages 1 and 2 of the EBCD process remained, not all projects used filmed narratives due to the time and cost implications. In addition non-participant observation and the celebration at Stage 6 were sometimes absent as they are not always viewed as intrinsic to the process (Donetto et al., 2014). However the recommendation is to retain these elements due to the rich contextual data that observation provides; and the role of the celebration and review event in evaluating progress; and maintaining relationships and ownership in the long-term impact of the study (Donetto et al., 2014).



The co-design activities of stages 4 and 5 were also viewed as complex and challenging by some, perhaps unsurprisingly given the traditional healthcare epistemology. As one EBCD researcher pointed out, moving between the role of ‘expert’ and ‘decision-maker’ to equal collaborator and partner may be a challenge for many healthcare professionals (Donetto et al., 2014). Responses to combat these issues and preserve important aspects of the approach include the accelerated version of EBCD, training programmes and free web-based support (The King's Fund, 2011, Donetto et al., 2014). Encouraging paradigm changes beyond the borders of the healthcare system itself were also suggested, such as seeking recognition and recommendation for the approach at a policy level (Iedema et al., 2010), and embedding the underlying principles of collaborative equal working at a training and certification level (Plsek, 2014).

Although EBCD efforts must consider several challenging aspects, the approach is recommended by many people who have used it and seen it play an important role in improving experiences in a wide variety of settings. Specific strengths of the approach include:

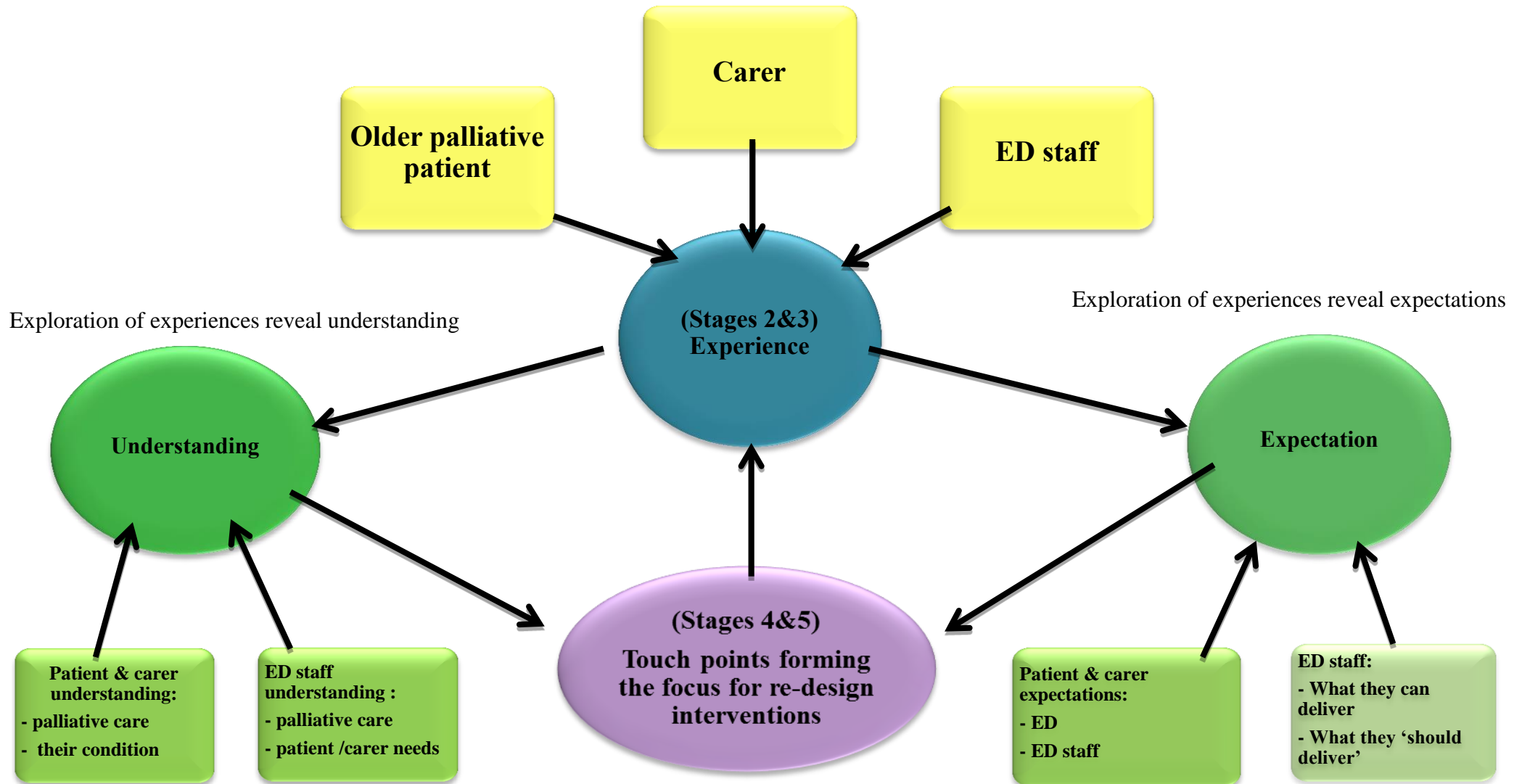
- increased patient and staff engagement in change activities (Donetto et al., 2014);
- a sense of ownership and community where staff and patients’ attitudes towards one another have been challenged positively (Tsianakas et al., 2012);
- organisations valuing the input of patients and carers more and moving away from the medical paternalistic paradigm (Iedema et al., 2010); and
- patients and staff reports of finding the process empowering, cathartic and making them feel ‘heard’ (Donetto et al., 2014).

Consideration of the approach, its strengths and weaknesses show that, while challenging, EBCD is a methodology that is designed to engage with and improve difficult human experiences in complex situations. Although EBCD has been used in emergency services (Piper et al., 2010b), palliative/cancer care (Tsianakas et al., 2012, Adams et al., 2013), and older person services (Bowen et al., 2011), at the time of writing of this thesis, there has not been an application to a combination of all three aspects. Therefore careful deliberation over how to identify the experiences of the participants, facilitate ownership and conduct the study was required.

### **3.9 Adaptation of EBCD to the study**

The focus on experience within the study is explicitly stated in the study aim: ‘to improve experiences of palliative care for older patients, their carers and staff in the ED’. In order to apply the principles and processes of EBCD to this aim, a conceptual framework was developed as a way of identifying, labelling and classifying key information about the experiences under investigation (Figure 9) (Huckabay, 1991). The conceptual framework was informed by the findings of the narrative review and the lack of knowledge about staff, patient and carer experiences. As already discussed, an experience of a situation does not stand alone in a person’s life; it impacts and informs both their understanding of the situation as well as their future expectations of it (Carr et al., 2001). Expectations in turn become ‘*a set of stable assumptions...learned from experience*’ (Carr et al., 2001).

Figure 9: Conceptual framework showing the application of EBCD to the thesis



Although there is fluidity between the three factors of experience, understanding and expectation, it is ultimately largely experience that influences a person's perceptions. These perceptions; the individual's 'experienced reality' (Bate, 2007), must be valued and acknowledged if the defining moments (touch points) of the experience are to be understood (Dewar, 2009). Put simply, by investigating a person's experiences of a given phenomenon, we are able to learn about their expectations and understanding of it (Carr et al., 2001). This understanding can then be fed back into practice and so influence experience (Carr et al., 2001, Grol et al., 2002).

The framework (Figure 9) demonstrates how identifying and responding to these expectations and understanding shaped the EBCD process to this study. At the beginning the population is identified: older palliative patients, their carers and staff. Then, through the data collection methods identified earlier (Stages 2 and 3), participants are asked to share their experiences of palliative care in the ED environment. The analysis seeks to identify the understanding and expectations of the participants in this context. Specifically: what do older patients and their carers understand about palliative care as it pertains to their treatment and condition, but also: what do they understand about their condition as a whole?

These data provide insight into why patients are accessing the ED and what they believe they need from it. For staff, the focus is first on their understanding of palliative care: what it is, who provides it, how and when it should be provided, and second on their understanding of the needs of palliative care patients and their carers. The narratives were also scrutinised to identify the expectations that underpinned these experiences. For patients and carers: what are their expectations of the ED, why are they coming to a department that is known to be loud and chaotic? More specifically, what are their expectations of the ED staff and the care they are expecting or hoping to receive compared to their perceptions of the care they actually received?

For staff, their stories are analysed to identify their expectations of the care they believe patients and carers are expecting them to deliver, and also their expectations of the care they believe they are *able* to deliver. This provides insight into staff attitudes, concerns and feelings about the patient group and palliative care. From these data touch points are identified and validated by participants who collaboratively agree improvement priorities based on these touch points, co-designing service improvements (Stages 4 and 5). Given the lack of existing knowledge around older palliative patients, their carers and staff in the ED,

the combination of this joint knowledge can also be fed back directly into wider discussions about what is known on the topic, and what the perceptions and challenges are for the UK.

### **3.10 Applying the Stages of EBCD to the study**

As noted above, it is not uncommon to see adaptations in AR/EBCD studies, as researchers need to be flexible and honest to the story they are exploring (Donetto et al., 2014). This study required several adaptations due to a number of factors which are explored further in the thesis. These were predominantly to do with:

- time constraints of undertaking the endeavour as a doctoral research project and lone researcher;
- lack of foundational knowledge and evidence about palliative care in the ED, meaning that staff data needed to be collected to provide context before patients were approached;
- challenges engaging the research site in the uptake of ownership and collaborative working, and
- the development of the study by the inclusion of an international fieldtrip.

As a result of these issues, the last two stages of the EBCD process were not included. An overview of the conduct of the study according to the six stages is given below to provide context as the narrative moves on.

**Stage 1: Setting up the project (Chapter Four):** This stage was an ongoing element as the study was developed externally to the research site. It was initially viewed with some apprehension and disinterest by the management of St Thomas' ED but with growing support and involvement as the study progressed.

**Stage 2: Gathering staff experiences (Chapter Four):** The lack of existing data about staff experiences of palliative care in the ED in general meant that foundational evidence was needed to identify if the progression of the study would be recognised and taken up by the research site.

Between Stages 2 and 3 a six month developmental digression to the study occurred with a visit to a geriatric-only ED based at Mount Sinai Hospital in New York (Hartocollis, 2012). Design principles and lessons for introducing services for older

and palliative care patients in the ED were developed for integration within this study and departmental redesign work at St Thomas' ED (Chapter Five).

**Stage 3: Gathering patient and carer experiences (Chapter Six):** This stage typically runs in parallel to Stage 2. However, engaging vulnerable older palliative patients and carers was delayed due to the likelihood that they would not survive the full timeline of the study (four years), the critical reflections explore this more fully.

**Stage 4: Bringing staff, patients and carers together in the first co-design event (Chapter Seven):** The thesis concluded with the co-design event.

**Stage 5: Ongoing co-design work in small groups:** Although the study officially ended at Stage 4, continuing development and improvement priorities were monitored and recorded as evidence of impact and data for ongoing work during the write-up phase of the thesis.

**Stage 6: A celebration and review event:** Regretfully this element did not occur but staff, patient and carer participants were kept updated with the progress and achievements of the study by personal communication.

### **3.11 Specific challenges and ethical considerations for the study**

Although various challenges of undertaking an AR/EBCD study have been addressed, there were standard ethical and project specific issues to be considered. Project specific considerations were mostly to do with the ethics of involving older palliative care patients and potentially bereaved carers. Chapters Six and Seven deal more fully with this undertaking, and Chapters Four, Six and Seven provide detail of the management of broad ethical considerations, for example:

- Gaining ethics and R&D approvals
- Recruitment
- Data collection and storage
- Anonymity and confidentiality particularly in relation to filmed footage
- Ownership of data and participant roles in the research including information and consent forms
- Withdrawing data, and
- Leaving the study.

The ethical principles listed are fundamental for any research project, but their management becomes more complicated when considered in relation to older patients with palliative or end of life care needs, whose acute and often rapidly changing conditions mean that they may not survive the research process (Black, 2008, Stone, 2009, Goodman et al., 2012). Despite such complications, all patients and carers deserve the right to be heard. There is evidence supporting the inclusion of vulnerable participants which demonstrates that they can not only provide powerful input into service redesign and consideration of factors beyond that of their immediate care, but they can also find the process a cathartic and fulfilling one (Black, 2008, Goodman et al., 2012).

### **3.12 Critical reflection**

In the Prologue I reflected on the selection of EBCD due to its resonance with my own ontology and epistemology. However, at the early stages of setting up the research and identifying the methodological approach, my stance as an interpretivist researcher was not as complete as I had believed. Although in theory I fully advocated for the individual voices of the patients, carers and staff to be expressed, heard and used for change, in practice I initially found it difficult to silence my own rather autocratic certainties over the needs and solutions to improving palliative care in the ED. Informed by a nursing background and stories from patients and colleagues, I was convinced, without realising it, that I knew the challenges of palliative care in the ED, as well as the solutions that would ultimately emerge.

Probing by my supervisors as I set the study up led me to reflect on this and I identified that my underlying ontology was at odds with the manner in which I was developing the study. It was only as I began to undertake the data collection and analysis of staff experiences, constantly reflecting critically on my questions and responses in interviews, that I was finally able to silence my own voice and become more appreciative of the perspectives of those actually at work in the ED. Hearing the ED staff perspectives and experiences that I had not anticipated or did not agree with, and acknowledging my struggle to accept them was initially difficult. But by the time I began to engage with patients and carers I had accepted that I could not anticipate what they might say, and it would be unhelpful to attempt to do so. I found listening considerably easier and more enjoyable than earlier on in the research. This developmental process is reflected upon in more detail in the following chapter, and continued in Chapters Six and Eight.

There were other challenges to undertaking EBCD that I struggled to consider at this early stage. I was coming into an organisation and department that I was not part of, with a methodology that required input, time, space, endorsement and ownership from people who had not asked for the research or personally identified the challenges I was asking questions about. As the study progressed I struggled to stay true to the design of the methodology while frequently having to conduct activities as a lone researcher with initially little interest from the study site. Strategies to manage these challenges included a careful audit trail of all decisions (sections of which are included in the thesis), regular sessions with my academic supervisors to maintain accountability, and feeding back the progress and development of the work to the main gatekeepers at the site. Reflecting on the eventual involvement of older palliative patients and their carers, despite what I felt was a clear need for their participation, also raised uncertainties. I questioned whether I would actually be able to access, identify or recruit them to the study, let alone achieve their encouragement, engagement and ownership of the study, given the challenges inherent with such a vulnerable group.

These factors, coupled with my own relative inexperience as a researcher, raised concerns over my ability to complete a full EBCD study within the time frame. As has been discussed, this was not ultimately possible, but from the start I was aware of the possibility that this study had the potential to be the foundation for a larger piece of ongoing work.

### **3.13 Conclusion**

Having moved the narrative on from the literature and background, this chapter has sought to ground the research aim: to improve the experiences of palliative care for older people their carers and staff in the ED' in the methodological approach of the thesis; EBCD. In Chapter Four the narrative moves on to the first and second stages of the research process: the staff story.



## **CHAPTER FOUR: THE STAFF STORY**

### **4.1 Introduction**

The aim of this research is to explore and improve experiences of palliative care in the Emergency Department (ED) for older patients, their carers and the ED staff. The previous three chapters provided context and background to the study. This included the challenges of caring for older people who are living longer with co-morbidities and have a growing need for social and medical support (Davies, 2004, British Geriatrics Society, 2008, National End of Life Care Intelligence Network, 2010) leading to increased use of the ED. This patient group is outside of the traditional ED demographic, thereby challenging the structure of the existing model of emergency care (Grudzen et al., 2011a).

The narrative review reflected on the limited data exploring these challenges for EDs to provide care that extends beyond the ‘resuscitation, stabilisation, transfer’ model (Eby, 2008, Couiliota et al., 2012). Of particular relevance to this chapter was the fact that some ED staff may not perceive that they even have a role in provision of palliative care (Smith et al., 2009, Grudzen et al., 2011b). The selection of EBCD as the research methodology for the study enabled patients and carers to work with staff, having a shared and equal voice in improving experiences of palliative care in the ED (Bate and Robert, 2007). Stages 2 and 3 of the EBCD process traditionally run in parallel; however, the lack of UK data on ED staff views and experiences meant that foundational exploration was required within the research study site.

It was important to identify the views of the staff in the ED towards older palliative patients and carers, along with the staff experiences, expectations and understanding of the issues and barriers in providing care. This would reveal if the need for the research would be recognised by ED staff and management, and also if the collaborative elements of the research could feasibly be conducted.

### **4.2 Chapter overview**

The purpose of this chapter is to lead the narrative through Stages 1 and 2 of the EBCD research process. Stage 1 describes setting up the project and Stage 2 discusses the detail of gathering and evaluating staff experiences. The narrative then resumes the first person voice in a critical reflection of the challenges, opportunities and decisions underpinning these early stages of the EBCD project.

### 4.3 Aims and objectives of Stages 1 and 2

The undertaking of Stages 1 and 2 are discussed further below but their aims were as follows:

- Stage 1: to manage the study practicalities and set up the project
- Stage 2: to investigate the experiences of palliative care in the ED from the perspective of ED staff.

The aims of Stage 2 were addressed by the following methods:

- Conducting interviews with nursing and medical staff, from newly qualified to consultant level, to lay the foundation for the work
- Using the interviews to identify issues raised by palliative admissions, specifically:
  - experiences of care delivery
  - perceptions of the needs of palliative patients and their carers in the ED
  - views of staff in regards to their role in this process.

During the data collection, with the permission of the ED management, photographs were taken of the ED during quiet periods where it was empty. These photographs are included within this chapter as illustrations.

#### **Secondary aim**

An important task for an external AR/EBCD researcher is to understand the ‘micro politics’ of the research setting, such as resources, processes and hierarchies (Smith et al., 2010b). Therefore, due to the lack of existing data on patient and carers’ experiences as well as staff experiences, two additional lines of enquiry were undertaken as fact finding exercises to give context to the systems, processes and experiences shared by the ED staff. The aim of each was to identify objective data about the impact of ED staff on an older palliative patient’s experiences in the ED.

This additional data collection took two forms. First, interviews were conducted with two clinical coders and a palliative care consultant to determine if and how palliative patients are identified through the documentation generated by ED staff. Clinical coders translate descriptions of medical diagnoses and procedures written by medical staff into standardised codes, which record healthcare data and inform hospital episode statistics. The second form of data collection was observation of a series of post-take consultant ward rounds (PTWRs), followed by an informal interview with the consultant to gain insight into the process that a patient experiences, including how ED documentation and handover identifies the palliative

care status of the patient. A post-take ward round is the name given to the first ward round a patient will experience if they have been admitted to an Admissions Ward from the ED. The aim is to review the patient and determine their care plan and pathway, either into another more suitable ward or to be discharged home. These two data sources provided insight and information on hospital processes and procedures, and the role of the ED in recognising patients who were in need of palliative care.

These additional data were not included in the data collection and analysis of Stage 2, but rather they were used for reflection to inform and expand the understanding of systems and the patient journey from the ED at Guy's and St Thomas' NHS Foundation Trust. A short discussion is provided reflecting on the conduct and findings at the end of this chapter.

#### **4.4 Stage 1: Setting up the project**

Stage 1 of the EBCD process 'setting up the project' involved identifying, approaching and gaining access to the study site; building and maintaining relationships with local gatekeepers and collaborators; gaining ethical approvals; and data management.

##### **4.4.1 St Thomas' ED and its local population**

Early plans for the research proposed conducting the study across three London teaching hospitals in order to generate comparable data and a wide range of experiences. However, during early stages of planning it became evident that this was beyond the scope of the thesis. In consultation with the study supervisors, the research study was restructured to work solely with one hospital: Guy's and St Thomas' NHS Foundation Trust (GSTT). GSTT is a large teaching hospital based in central London serving a diverse population, with an estimated 9.1% of the local population aged 65 and above (Beynon et al., 2011). Annually the ED sees records approximately 171,500 ED attendances, of which an estimated 16,435 are aged 65 or older (Guy's and St Thomas' NHS Foundation Trust, 2012, Henderson, 2015). Although this meant data were from one site, a recently published study demonstrated that St Thomas' ED has a high frequency of admission by older palliative patients who are often discharged with unmet palliative and end of life care needs (Beynon et al., 2011). In addition there were existing contacts at the organisation that could provide access to gatekeepers within the ED.

A full redesign of the emergency care services and physical layout at St Thomas' ED was underway while this study was being conducted, although the actual remodelling did not start

until its completion. The physical layout of the ED during the study had three main clinical spaces leading off from a large waiting room. A seven-bed minor injury room known as 'Minors' catered for patients with non-critical injuries (Figures 10 and 10). The patients recruited to the study were cared for in one or both of the other two rooms: a 16-bed major injury/incident room, known as 'Majors' (Figures 12 and 13), and a five-bed resuscitation room with a sixth single paediatric bay (Figures 14 to 16). Resuscitation also contained a family viewing room for bereaved relatives inside the department, and a family waiting room next to resuscitation. Other features of the ED were: a paediatric ED located directly next to the main waiting room; a small radiography department; a small area with four rooms used for teaching, training or storage which linked the Minors area to the paediatric ED.

#### **4.4.2 Building and maintaining relationships with the site gatekeepers and collaborators**

Contact was made with an ED practice development nurse (PDN) via a source at GSTT, who then took the role of gatekeeper and collaborator. The other central collaborator was the clinical lead for the ED. Initially the consultant in this role was cautious of the aims of the study and agreed access to staff for interviews, but not for the full EBCD study. Towards the end of Stage 2 the role of clinical lead was taken on by a different consultant in the department. They were more supportive towards the project and became the lead gatekeeper to all site activities and meetings, as well being named on ethical and R&D applications and providing access to patients, carers and medical staff. The development and maintenance of these relationships is considered in more depth in the critical reflection at the end of this chapter.

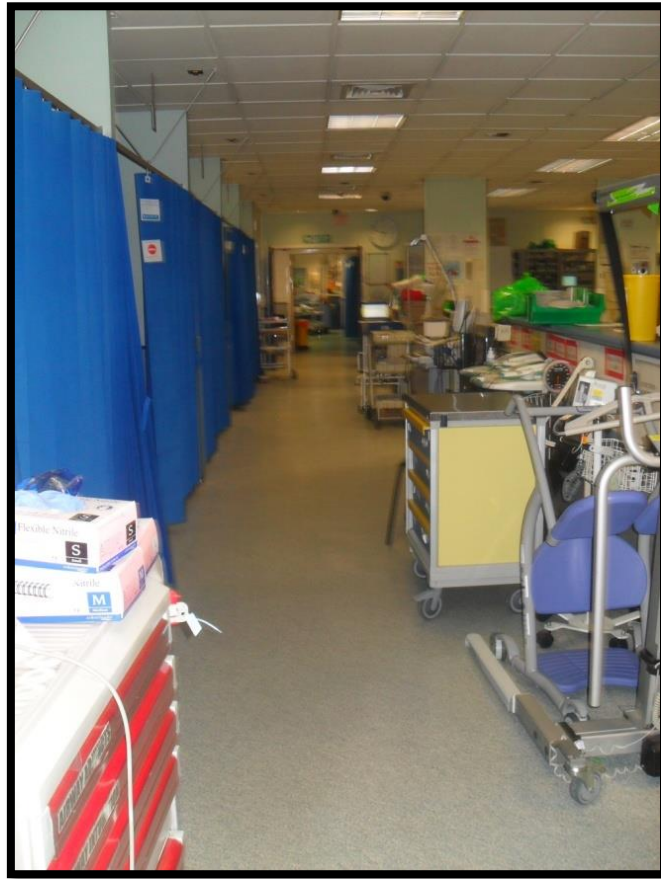
**Figure 10: 'Minors'**



**Figure 11: 'Minors' two patient bays**



**Figure 12: 'Majors'**



**Figure 13: 'Majors' patient bay**





**Figure 14: Resuscitation**



**Figure 15: Resuscitation Nursing Station**



**Figure 16: Resuscitation patient bay**



#### **4.4.3 Ethical and R&D approvals**

As it was unclear whether the full EBCD study would be possible, ethical approval was initially sought only for the data collection of Stage 2. Approval was granted by King's College London Ethics Committee (PNM/11/12-57). Approval from the Guy's and St Thomas' Research and Development office was sought and granted via the Integrated Research Application System (IRAS). A modification of the proposal was later submitted and approved to extend the work with the ED to include the researcher's feedback of the analysis and validation exercises with staff.

#### **4.4.4 Data management**

Data were managed as per the requirements of the Data Protection Act 1998 (Department of Health, 1998). All participants were given an information sheet and consent form outlining the purpose of the research, their role and how their data would be stored and protected (Appendix 1 and 2). Interview data were anonymised before being sent for transcription by an external company. Electronic data were stored on King's College London's secure network. Hard copies were secured in a locked filing cabinet in the locked office provided for



post-graduate student research. Research data will be kept for four years after project completion in accordance with College protocol, after which it will be destroyed

#### **4.4.5 Participant selection criteria and sample**

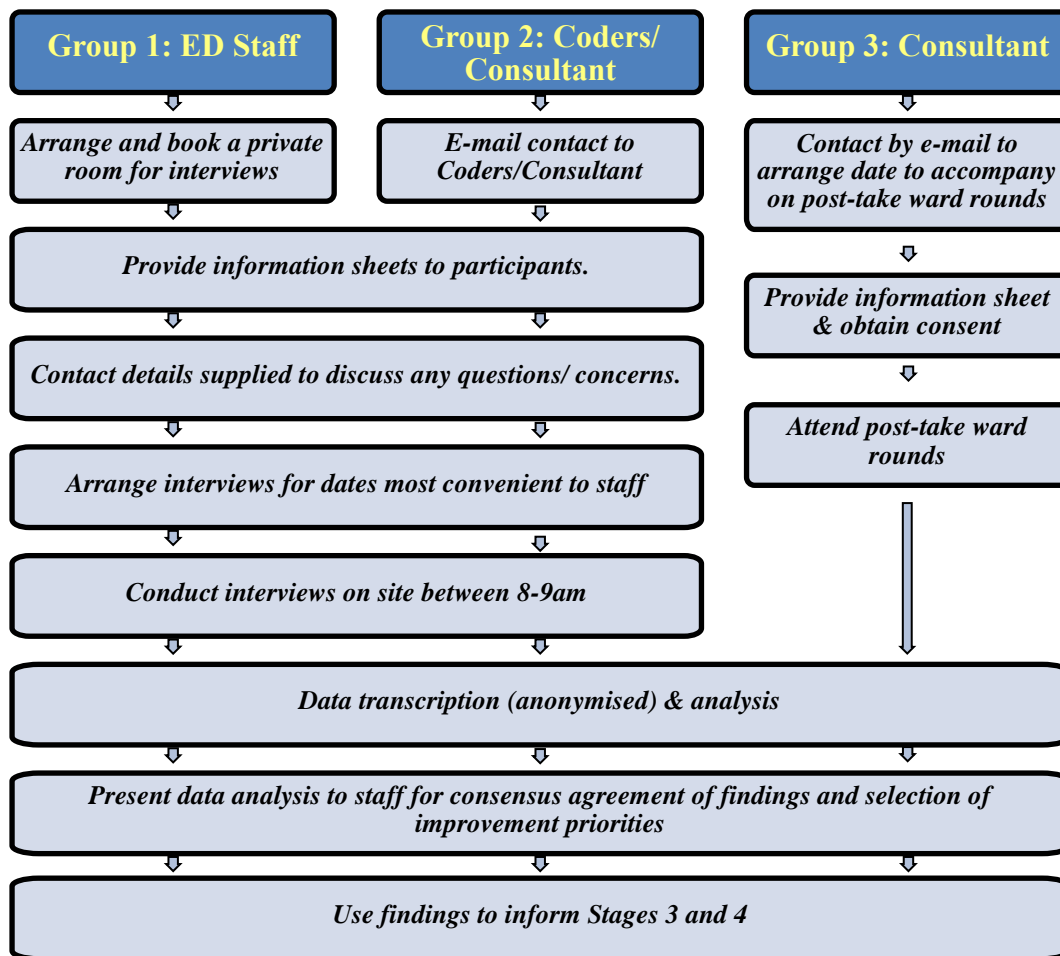
There were three groups included in Stage 2 (Figure 17). Group 1 comprised nurses and doctors working as part-time, full-time or agency staff at St Thomas' ED. The exclusion criteria for Group 1 were any non-healthcare provider working in the ED, including paramedics. Paramedics were excluded on the basis that their system of working, training and processes differ considerably to ED-based staff. Fifteen interviews were conducted within Group 1. This sample size was selected on the basis of the configuration of practitioners in ED. The need for comprehensive understanding of palliative care experiences meant that it was necessary to interview nurses and doctors at each level of care provision, from those delivering hands on care to those with more senior and management roles. Therefore a purposive sampling strategy was employed for staff interviews (Mason, 1996). The aim of the data collection was to gain insight into the general understanding, experiences, and opinions of ED staff caring for older palliative patients in the ED.

Groups 2 and 3 served the secondary fact finding aim. Group 2 comprised two clinical coders and a palliative care consultant. The data collected were from interviews about palliative care coding. Group 3 comprised a post-take ward round team of doctors and a pharmacist. Data collection included observing three ward rounds and an informal interview with the leading consultant on the rounds. There were no exclusion criteria for Groups 2 and 3.

### **4.5 Stage 2: Gathering and evaluating staff experiences**

The process of gathering staff experiences involved data collection, analysis and validation of findings with staff. Figure 17 presents a summary of these research processes. The fact finding data collection exercises are included in this figure as they were collected concurrently.

**Figure 17: Conduct of Stage 2**



#### 4.5.1 Recruitment

Recruitment for the data collection was facilitated and supported by the PDN and Clinical Lead. Initially the PDN and Clinical Lead facilitated recruitment by identifying potential participants via an all staff e-mail. The PDN also offered a room on-site for interviews provided they were conducted between 8am and 9am, as well as providing shift cover for participating staff during this time. The rationale for this was that handover from the night to day shift ended at about 8am and this was generally the quietest time of day within the department. Only one staff member responded to the e-mail and two further interviews were agreed with staff who were present in the department at the time of this interview. The recruitment process was revised to allow the researcher to be present in the ED to recruit staff in person which was found to be more fruitful. An unanticipated snowball effect occurred as participating staff recommended the study to their colleagues. A personal presence in the department proved valuable for building relationships with staff, observing the ED, raising interest in the study and providing a more informal route for recruitment.

Similarly to the staff recruitment, the clinical coders and palliative care consultant (Group 2) and post-take ward round consultant (Group 3) were identified and contacted via the ED Clinical Lead. All were contacted by e-mail with copies of the information sheet and consent form. Of the two coder interviews, one was with a non-specialist clinical coder to explore coding of palliative care patients in general, and the second was a data manager working with the palliative care team monitoring palliative care coding at GSTT to support the work of the palliative care team. The consultant leading the post-take ward rounds was also initially contacted over e-mail and agreed to the observation of three rounds and an informal conversation to review any questions that arose concerning the PTWR.

## **4.6 Data collection**

### **4.6.1 Group 1, ED staff**

The room assigned for conducting the staff interviews was a teaching room situated near the main waiting area. Although this was a very useful location, at times it could be quite loud and the tannoy system often cut across interviews. Prior to the interviews, staff participants were given time to read a copy of the information sheet, and the chance to ask any questions about the research and to sign a consent form. These documents were stored securely in a locked cabinet in a locked room at King's College London.

The interviews were semi-structured, lasted approximately 40-60 minutes and were audio recorded. A topic guide (Appendix 3) was used in each interview that explored definitions, understanding and experiences of palliative care provision, education and training, and thoughts on how the delivery of palliative care could be improved. Four kinds of data were kept from each interview: a copy of the audio recording; the transcript of the interview; reflective field notes on the interview considering the interactions with the participant and comparisons to other interviews; critical self-reflection of the style, content and conduct of the interview (Appendix 4); and interview notes. Interview notes were points made against the topic guide that served as a summary of the interview and early stage of analysis. On completion of each interview the audio recording was sent for external transcription, and the field notes were documented to establish and maintain an audit trail.

Unlike the patient and carer interviews, staff interviews were not filmed. This was to protect the anonymity of the staff and the confidentiality of the patients they were reflecting upon. Furthermore, ED staff are 'frontline' healthcare staff who can be targeted for abuse, therefore

filming them for a DVD that had potential for wider use in later dissemination and teaching could prevent them from opening up about their experiences, but also put them at personal risk.

Field notes were a useful reflection tool that developed and improved the quality of interviews. For example, the first two interviews started with a long introduction including a definition of palliative care. On reflection and advice from the study supervisors the introduction was removed from the interviews and an open ended question about the participant's perception of palliative care was asked instead. This change, as the data analysis shows, resulted in identification of key information about the barriers of palliative care provision in the ED. Figures 18 and 1924 give examples of the field notes from the third interview undertaken with a staff nurse with six years ED experience. The LCP was frequently mentioned by staff as seen in the following extracts. Its removal in the third year of the study had a significant impact on their confidence in providing palliative care.

**Figure 18: Extract from topic guide notes**

**Existing understanding**

- What is your understanding of palliative care – distinguish between EoL/PC?

*I did not ask this directly but she gave the answers in her comments by linking PC to the end stages and with frequent reference to the Liverpool CP (see field notes).*

- View of the existing palliative care provision in A&E?

*She seemed to struggle with a conflict; she is providing PC but has constraints, e.g. time and knowledge of patient's condition. While she says she is giving PC, she struggled to define how this was done. However, she did highlight a few things that the department does for families who lose someone in A&E. e.g. sending out a card 6 weeks after death to say thinking of you. The sudden, unexpected deaths seemed easier to manage, rather than PC ones, even when there was a plan. When talking about family expectations she made comments around wondering quite what they expected her to be able to do, saying she often felt mean when she had to say they can't do anything more.*

*Made reference to the difference between doctors and nurses attitudes; Drs being concerned with saving lives, nurses with making them comfortable. She referred to (though not in these words) death meaning the health profession often thinks it has failed or lost, and that death was now so often in hospitals, even when people want to die at home, the strain for their carers is often too much leading to 'family panic'.*

*Reference to previous use of 'files' with details of local PC patients: she did not know where these files were now or who had set them up or updated them. However, when patient details were present it did help in the care of a couple of patients. Difficulties emerge when PC were from other areas and just visiting London. However this system does not seem to be in operation any longer. A similar file exists for other patient groups with a disease 'passport' such as COPD and sickle cell. This contains information of last visits and key clinical information.*

**Figure 19: Extract from field notes**

General and participant specific field notes

- She had a lot of interesting points about PC in ED. I inadvertently challenged her perspective on PC patients and what could be done by mentioning COPD patients and asking when she felt that PC should begin and what did she mean by 'we could do more'.
- She frequently linked PC to the Liverpool Care Pathway; this seemed to be almost like a crutch for containing this patient group. By this I mean that ED staff need a wide range of knowledge for all and every condition; a pathway is a vital tool to enable good timekeeping and following processes and there are several in operation. Their impact is to give busy staff a guide to follow to ensure that all the necessary 'checks' are done. The LCP seemed to have this sort of role: rather than being a guide, when it was referred to or considered it was seen as an absolute. When discussing the LCP it gave her some structure to help understand PC patients and the needs she would have to consider.

Field notes – Self-reflection

- This interview was the best one to date in terms of my own interviewing skills. I spoke far less and considered the questions I wanted to ask more carefully. She gave far more information and I was more aware of listening out for cues to prompt for more information.
- I found that because she had so much to say it was occasionally difficult to link back to a point she was making if she was then making a new, equally as interesting point.
- I didn't jot down key words because I forgot and by the time I remembered the interview was in full flow and my searching for a pen would have thrown things off. I will do this next time.
- At times I felt that she was looking to me for confirmation of her practice and I think at points I did give this as encouragement is something I find very natural. However overall I managed to just nod and look enquiring. On reflection I could have probed about this – asked about her confidence around her practice.

The characteristics of the fifteen staff interviewees were recorded, showing the gender and age, clinical role within the ED, and the number of years of ED experience. This record (Table 6), acts as an additional part of the audit trail, providing factual information about the participants. The mean age of the participants was 35 (range: 27-49), median ED clinical experience was six years (range: four months to 20 years), and 73% were female.

**Table 6: Characteristics of staff participants**

Interview No#	Gender	Age	Role	ED Experience
1	F	34	F2 (Senior House Officer equivalent)	4 months
2	F	33	ST2 (ED Registrar equivalent)	6 months
3	F	30	Staff Nurse	6 years
4	M	34	Senior Staff Nurse	4.5 years
5	F	27	Staff Nurse	14 months
6	F	31	Sister & Emergency Nurse Practitioner	7 years
7	M	38	Staff Nurse	15 years
8	F	42	Practice Development Nurse	18 years
9	F	29	Staff Nurse/Bank Nurse	1 year
10	M	49	Emergency Consultant	20 years
11	F	44	Emergency Consultant	18 years
12	F	35	Deputy Sister	6 years
13	M	31	Registrar	2 years
14	F	37	Staff Nurse	6 years
15	F	43	Emergency Consultant	19 years

**4.6.2 Group 2, Clinical coders and palliative care consultant**

The interviews with the coders and palliative care consultant each lasted approximately 40 minutes. These were also semi-structured, using a separate information sheet and topic guide (Appendices 5 and 6). The interviews were audio recorded and transcribed, and field notes were made. The topic guide focused on staff documentation, the application of codes to clinical notes, and the strategies in place to recognise palliative patients from these clinical notes. The interview with the palliative care consultant also explored the practice of coding, its implications and challenges. The interview went on to question some of the issues highlighted by ED staff such as the management of palliative care patients and the palliative care services available at GSTT.

**4.6.3 Group 3: Observation of post-take ward round and informal interview**

Three PTWRs were observed, although initially only one had been planned. The first was a useful and informative exercise but there were no palliative care patients, which was viewed as atypical by the team conducting the round. On its completion an informal interview, with ethical approval, was conducted with the leading consultant to discuss issues that arose during the round. While some interesting insights into hospital processes were gained, at the invitation of the consultant it was deemed appropriate to observe a further two rounds to try to witness the transitions of older palliative patients from the ED. Descriptive field notes were made during the PTWRs containing information about: the management and staffing of

the rounds; reflections on communication and palliative care; challenges to the provision of high quality care; the patient journey; and the possible researcher impact on the rounds. Several case studies were also documented with the permission of the patients concerned, which excluded personal identifiers. The PTWRs lasted approximately four to five hours and were usually staffed by a team comprising six doctors and a pharmacist.

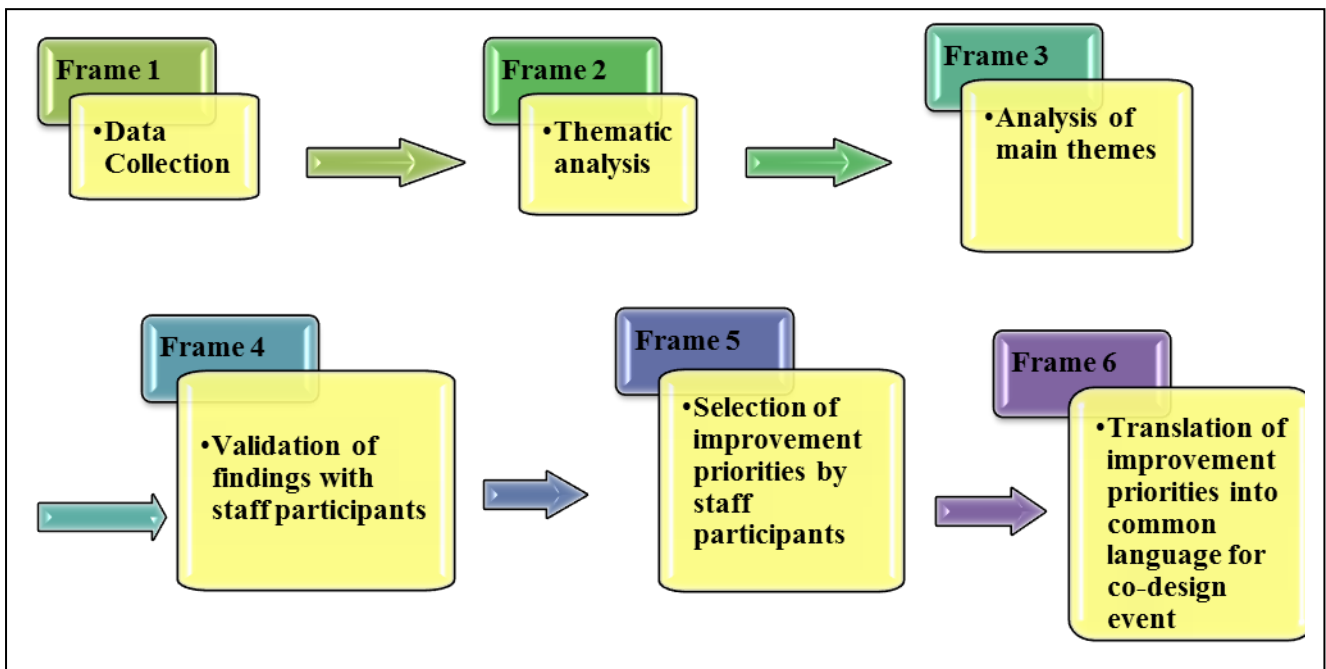
#### **4.7 Data analysis**

The topic guide for the staff interviews focused on the knowledge, attitudes, experiences and predictions that staff had about older palliative patients and palliative care in the ED. The purpose of data analysis here was to explore interviews for the main themes that emerged and then to validate these with staff. Following an EBCD approach the staff then collaboratively selected three themes that they felt contained the main improvement priorities for palliative care in the ED.

Moving the data through this process, from the original interview format into three succinct priorities that could be explored alongside the patient and carer data at the co-design event (Chapter Seven), was done in six steps. These steps drew on a grounded theory approach (Holloway and Todres, 2007) and are presented as a series of frames of analysis that show the iterative comparison, coding and development of core concepts concerning the staff experience of palliative care in the ED (Figure 20).

Frame 1 refers to the data collection with the ED staff. Frames 2 and 3 analysed the data and identified the main themes. This was initially conducted independently and then reviewed with the study supervisors before being verified by ED staff in Frames 4 and 5. This two stage review/verification process was designed to reduce researcher bias, and to ensure transparency and rigour in the analysis (Green and Thorogood, 2009, Froggatt, 2013). Frame 6, the translation of improvement priorities into common language in preparation for the co-design event, took place after the patients and carers had selected their improvement priorities (Chapter Six).

**Figure 20: Frames of analysis**



#### **4.7.1 Frame 1: Data collection**

The previous section outlined how the data were collected and an ongoing audit trail was kept recording detailed notes on each interview. This served as early analysis in the form of familiarisation with data and to help identify themes.

#### **4.7.2 Frame 2: Thematic analysis**

Once transcribed, data were analysed using a thematic framework analysis which provided a systematic approach that aimed to ultimately produce practical strategies for improving palliative care in the ED (Green and Thorogood, 2009). Early stages of the analysis were undertaken supported by the software NVivo8. However, through personal preference more traditional methods replaced this, such as using hard copies of interviews, colour coding and creating tables to chart and code the data. The conceptual framework introduced in the previous chapter (Figure 9, Chapter Three) provided the structure for the analysis by mapping the way that understanding and expectations were investigated in interviews. This helped to identify the factors at the root of staff experiences while maintaining the focus of the thesis.

There were three steps within Frame 2 which drew on the processes of open and axial coding in Grounded Theory (Green and Thorogood, 2009). In step one, interview transcripts were read using the ‘expectations and understanding’ elements of the conceptual framework and topic guide to maintain the focus of the study (Appendix 3). Open coding, quotes, case



studies and terms that related to knowledge, attitudes, experiences and thoughts about the future of older palliative patients and palliative care in the ED were highlighted. Then mini themes, also known as ‘second level categories’, were identified from these quotes, case examples across the fifteen transcripts.

The third step of Frame 2 used axial coding to extract and tabulate the transcript data to identify broad themes that encapsulated the second level category themes. An example is given in Table 7 which contains an extract from one of these broad themes: ‘Systems and Processes’.

**Table 7: Extract from Frame 2 thematic analysis ‘Systems and Processes’**

Theme: Systems and Processes		
Int.	Pg. No.	Quote/Term
1	9	<i>unfortunately that’s what A&amp;E is like, isn’t it, because everything has to happen in four hours, and it’s not just for palliative care patients, that’s like a general frustration, is that you can’t really deliver much else than just immediate treatment...And then patients I’m sure feel like they’re just being carted in, carted out, they get moved even in the space of the time that I’m seeing them to a different part of the hospital, and it is very dehumanising I think</i>
2	12	<i>...because the point of A&amp;E... well the point of A&amp;E is to resuscitate someone and then decide what to do with them next. Give them the life-saving treatment or the treatment that they need, pain relief and then get them to the next point where the specialist doctors can take over in with safety. I just suppose I would want that to happen as soon as possible but a bit less frantically maybe. Because I think the point of it is to be calm and know the plan and know that you don’t... you shouldn’t be making anything new up on the spot, sort of thing.</i>
3	3	<i>I didn’t know how to access palliative care for him from the A&amp;E. I basically said to him, ‘Go back to your GP, ask again about a Macmillan team or a support, maybe counselling and get the pain relief sorted.’</i>
5	22	<i>...I always think, ‘Oh, you know, did they want to end up here? Is that what their wishes were?’ But it’s not always up to them because it’s quite often taken out of their hands by that stage.</i>
9	2	<i>... a lot of the times, especially during the night you can’t get a direct referral over, so they’d have to come onto the medical wards. So it always sort of sticks in your mind that that’s what happened, particularly with the palliative patients that come in, they don’t necessarily go to the appropriate place.</i>
10	22-23	<i>.. ... Especially at night time when I was a registrar, it’s relentless. You see somebody really elderly, frail, and suddenly you have a violent drug abusive vomiting over you. It’s the nature...So you cut off, you deal with it, you’re evaluating your threat. Overall it does affect you. The shop floor is emotionally quite strong, powerful event.</i>

From the third step eight broad themes were identified:

**Age:** Issues specific to providing care for older and older palliative care patients in the ED, e.g. variation in attitudes towards older people influencing the likelihood of involving them in decisions about their own care.

**Barriers:** Issues relating to a lack of information about patients on admission to the ED and the ways in which different services were or were not working together, e.g. a frequent lack of information about ceilings of care and resuscitation orders.

**Communication:** Issues relating to communication that impacted on care delivery for older palliative patients, e.g. communication between services inside and outside of GSTT.

**Palliative care:** Challenges around understanding what palliative care is, e.g. who should provide it, and when and how it should be given.

**Roles:** Issues around roles in palliative care provision in the ED and wider healthcare system, e.g. differences in understanding of the roles of specialists and generalists.

**Systems and processes:** Issues relating to existing systems or lack of processes, e.g. accessing different services through challenging referral processes; I.T. systems within the hospital do not always share the same platform and this prevents access to patient information.

**Time:** Challenges for staff to provide the level and quality of care they wish to due to time restraints, e.g. the four hour breech rule.

**Training and education:** Issues relating to provision of palliative care training and education at pre- and post-registration levels, e.g. many staff do not recall specific palliative care training.

#### **4.7.3 Frame 3: Analysis of main themes**

Once the eight themes were identified Frame 3 scrutinised them in more detail. This was done by asking three questions of the tabularised interview data as it pertained to the themes:

What is the issue?

Why is it an issue?

Why does it matter?

As with Frame 2 the theme ‘Systems and Processes’ is used here, as an example (Figure 21).

**Figure 21: Frame 3 analysis of themes ‘Systems and Processes’**

<p style="text-align: center;"><b>Theme: Systems and Processes</b></p> <p><b>What is the issue:</b> Much ED care relies on algorithms and set systems and processes. However, use of palliative care and end of life care pathways varies amongst staff. Additionally, many systems and processes are unknown to staff members, or are overly complicated to navigate.</p> <p><b>Why is it an issue?</b> ED staff have differing experiences of training (within and pre-ED) and there is inconsistent dissemination of pertinent information to them. Different specialties play a role in staff knowledge and awareness of different systems and processes that may not link with the ED as part of their normal practice.</p> <p><b>Why does it matter?</b> Lack of awareness and access to support and resources for staff can lead to negative experiences for all those involved.</p> <p><b>Supporting quotes:</b></p> <p><i>“...when you talk to doctors about Liverpool Care Pathway, that’s something that they think ‘no idea what you’re talking about’...”</i></p> <p><i>“...they say ‘why can’t I go straight to Guy’s and present myself? But unfortunately the systems don’t allow that...”</i></p> <p><i>“...I didn’t think of looking for his palliative care plan, but I did know we did have some down at some point, but there were issues with the fact...a couple of times we looked for patients and they didn’t have plans in the book...”</i></p> <p><i>“I haven’t seen a pathway through A&amp;E...I think it would be useful...I don’t know what exists within the hospital beyond A&amp;E...I don’t know how much value it would be...but maybe identifying people, getting the right services, ultimately getting them out of hospital...I think that would be useful, but I do think we try to do that anyway”</i></p>
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#### **4.7.4 Frame 4: Validation of findings with staff participants**

Chapter Three discussed the need for staff engagement in the collaborative processes of an EBCD project, as well as the challenges in bringing about this partnership (Piper et al., 2010c, Boyd et al., 2012). Early on in the data collection it was unclear quite how this would occur given the restrictions placed on early data collection by the site gatekeepers. The relationship with the PDN was vital in this stage. During a discussion she was asked for the best route to feedback findings to staff for their approval and collaboration in selecting practical redesign priorities. She kindly provided space during a course of mandatory nursing staff development days to do this. A full summary and discussion of the sessions is given later in this Frame.

### ***Aims***

The sessions had two aims. The primary aim was to gain consensus on the data and identify improvement priorities. Frame 5 deals with the selection of improvement priorities in more detail. The secondary aim was to continue building on relationships that had been forged during the data collection to encourage ownership of the study. The invitation from the PDN to conduct the sessions over a six week period, also served as an encouragement that the study was gaining interest and growing support from the department.

To meet the first session aim, staff were reminded of the study purpose, and the data analysis was explained. They were then asked five questions:

1. Were the findings from the analysis shared by wider staff experiences?
2. Were there points that staff disagreed with?
3. Had any important issue been missed?
4. What were the three issues presenting the biggest barriers for patients and carers with palliative care needs in the ED?
5. What were the main three issues/priorities for change out of the eight listed themes?

Ideally the sessions would have focused purely on exploring the data and questions 1-4 allowing for reflection and analysis of the early validation by staff. Question 5 would have been the subject of later sessions that could focus solely on the three improvement priorities selected. The decision to include it was a pragmatic one based on time constraints of the feedback sessions and limited access to large groups of staff.

### ***Preparation: ethical approval and session approach***

In order to undertake the feedback sessions and gather this data, an amendment to the initial ethics application was submitted and approved by the ethics committee, along with new information and consent forms for staff regarding use of data gathered during the feedback sessions (Appendices 7, 8 and 9).

Building on learning from previous healthcare redesign efforts, the sessions were designed to foster a sense of ownership, inquiry and reflexivity rather than being directive (Lin et al., 2011). Advice was sought from two colleagues with previous experience conducting EBCD projects (Tsianakas et al., 2012). They also provided support during the six week feedback process where questions or concerns arose. Further input on methods for gaining trust and

engagement with ED staff was provided by a senior ED nurse working in a different hospital. This insight proved invaluable and the sessions emphasised the expertise of the staff, asking probing questions that drew on their knowledge and experience of practice and patient care (Lin et al., 2011).

The sessions were located in St Thomas' ED conference room used for teaching, shift handovers and meetings (Figure 22). Initially the sessions were to run for one hour over six consecutive weeks. Each session was divided between providing a basic overview into palliative care (requested by the PDN) and feeding back the findings, encouraging discussion and debate over the interview data. This time was shortened to half an hour due to changes in the department, and the six sessions were reduced to four.

The PDN reported that she had been told that the ED were 'over-developing' staff by giving them four development days a year and they had been cut back to two. This change highlighted some of the issues emerging from staff interviews regarding a perceived lack of understanding from higher management on the role of the ED and demands on staff knowledge. A fifth hour long session was conducted with registrars and consultants at the invitation of the clinical lead. Further sessions were offered with medical staff but regrettably these overlapped with the data collection trip to the US (see Chapter Five). However, feedback from the US trip was requested by all staff and was provided in subsequent teaching sessions (see Chapter Eight).

The sessions with the nursing staff were at 3pm, in-between other teaching sessions. They were adapted to the shorter time frame but this prevented setting up the room to facilitate group discussion (Figure 22). The session with the medical staff was at 11am and on this occasion the feedback session was the first, allowing for more flexibility. All sessions were held as part of mandatory training days.

**Figure 22: ED conference room used for feedback sessions**



### ***Delivery of sessions***

The data were presented to staff using the same format of the analysis in Frame 3: What is the issue? Why is it an issue? Why does it matter? A fourth question was included ‘What next?’ which was designed to move discussion beyond the challenges and into potential solutions in preparation for the co-design event. Eight posters were made providing the four questions as they applied to each theme. At the bottom of each poster were between three and five quotes from the interview data from which the theme had been identified (Figures 22-24). The posters were left with the PDN who put them up around the room at the start of each study day. This allowed staff the opportunity to read them and become familiar with their content prior to the session. The sessions were audio-recorded and another PhD student who is also a nurse attended to take notes and help to distribute and collect any documentation relating to the session. Again in view of the time constraints, the PDN agreed to distribute the consent and information forms prior to the sessions so that staff could read them and decide if they were happy to participate. In practice this was not always possible and at times the staff were completing forms while the sessions were in progress. At the end of each session staff were asked if they wished to participate further in the study by attending the co-design event. A number of staff expressed an interest and gave their contact details on the sign-up sheet provided.

Figure 23: Poster display

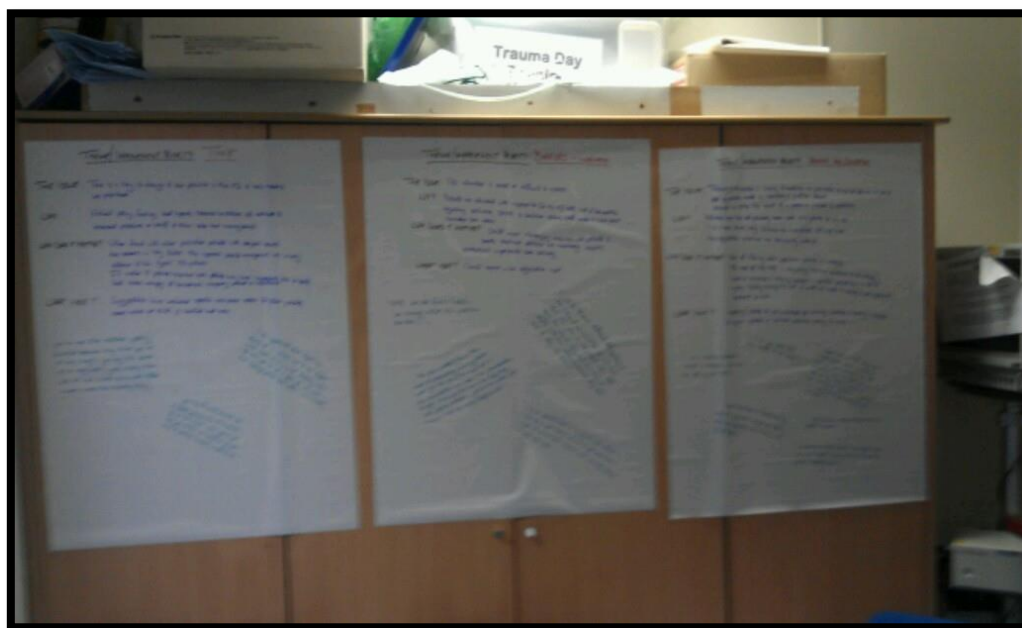
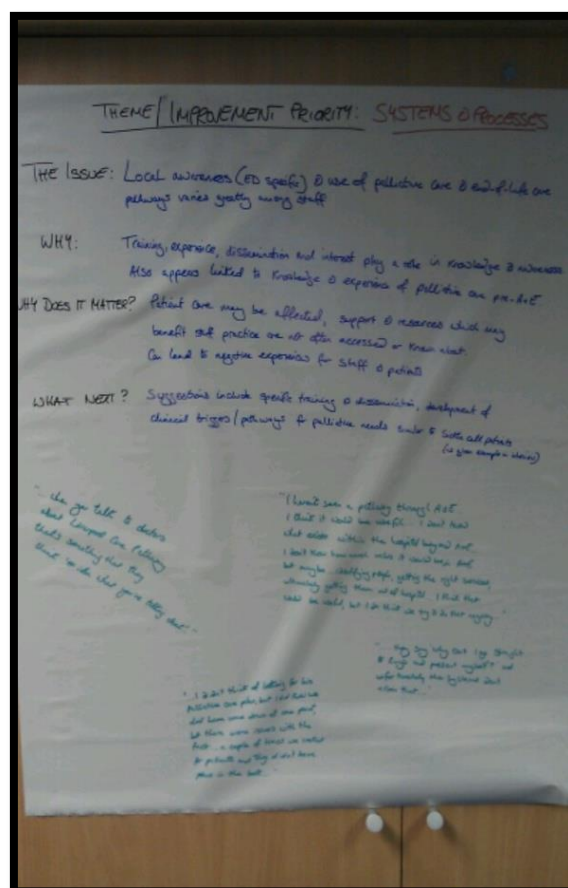


Figure 24: Poster detailing the theme 'Systems and Processes'



### ***Session management and reflection***

During this part of the EBCD process, the critically reflective audit trail involved the researcher listening to the audio recording of each session and completing a feedback and reflection form for each feedback session. This document was designed to identify the main points from the discussion: what had gone well, what was challenging and what needed to be altered to improve the clarity of the feedback for the next session (Appendix 10). The notes made by the PhD colleague were invaluable as her insight on the sessions offered a different perspective and critical appraisal.

The medical staff session was longer than those held for nursing staff and so the delivery was reconsidered. Reflection of the nursing sessions had identified that not all the nurses read the posters. Therefore the poster data were transferred into a PowerPoint presentation as this is a way of working that staff are more familiar with. This process was enhanced by a doctor working as a clinical fellow focusing on end-of-life care in the ED. The clinical fellow provided valuable insight into how to present the findings to medical staff, suggesting certain factors that might lead to discussion, such as the inclusion of particular interview quotes. This was another opportunity for staff engagement and ownership in the EBCD process which proved beneficial.

Each session had its own challenges and the reflective process at the end of each was a useful mechanism for improving the subsequent sessions. Figure 25 provides a summary of each session from the field notes which outlines some of the challenges and staff interactions.



**Figure 25: Summary of feedback sessions**

Session 1

In the first session the previous speaker ran over their time and instead of 30 minutes I only had about 15. However I was still able to gather a remarkable amount of data. The ranking sheets were not filled in correctly in the majority of cases so the ranking sheets were edited for clarity. I also took the time in the following session to explain how to complete them in more depth. There were 10 staff members present and about six participated actively in the discussion. Four gave their e-mail addresses to be contacted about the co-design element of the study.

Session 2

In the second session there were 16 staff members present but again, only about seven took part despite active encouragement and sometimes direct questioning, for example 'do you agree?' and 'have you experienced this?' I came away feeling quite despondent although my colleague said that I was much more confident and inclusive this time. In addition the PDN had not had the chance to hand out the information and consent forms so staff were trying to complete them as well as the ranking forms during the session. One staff member did not want to participate actively so they sat in the session but did not join in the debate. Not all of the ranking sheets were completed. Those that were completed were overall completed accurately according to the ranking system. One e-mail address was provided regarding the co-design event.

Session 3

The third session contained 10 staff members, eight of whom actively participated. This seemed to be a better number as there was more space for staff to see each other and less pressure on them as they responded. All completed the ranking sheets, though none gave their e-mail addresses but this session felt a lot easier to manage and direct. Preparation and reflection on the previous sessions were a big factor in this (Appendix 10). Timing was an issue as the previous session over-ran again and the speaker was again very slow to leave. This was reflected upon and strategies put in place to respond professionally and clearly so that my sessions were not further hindered by loss of time.

Session 4

This was the final session with nursing staff. Approximately fifteen staff members were present, the majority of whom participated. My colleague who had accompanied me previously to all sessions was not able to make this session at the last minute and I did not have time to make note of how many people were present and participating. However, it appeared that most did and all completed the ranking forms. Six also provided their e-mail addresses. This session was one of the easiest to take; although the group was quite quiet they did engage in the topic and a number shared stories. In addition I was able to make contact with the palliative link nurse for the ED, who approached me and gave me her e-mail address. Time was not an issue and I feel that my abilities in presenting and my confidence have vastly improved throughout this series of sessions.

Session 5

This was the final feedback session. There were eight senior medical staff members present, all of whom participated actively in the discussion and completed the ranking form. I was with a medical colleague who works in the department and who helped to facilitate the discussion. Her presence was extremely beneficial as she was able to present detailed scenarios and case studies to extract information. Staff were vocal and had many strong, often conflicting opinions and experiences. This was in keeping with my interview data. However there was full agreement with the analysis and development of the themes and there were several interesting suggestions for potential changes which were documented. Staff were interested in the study and its development and three provided e-mail addresses to be contacted for the co-design element. In addition I received a big compliment when one stated that it was one of the best sessions they have had. It ran over time and only ended when the next session needed to start. A key lesson was the use of power point: it was a much easier method of presenting these data and appeared to have more of an impact on staff.

### ***Validation summary***

In total 64 nurses and doctors were present at the feedback sessions, although not all actively participated. The eight themes were presented with quotes and examples from the data. An open discussion followed in which staff were asked for their views on the data presented, if it accurately represented their experiences, and if they felt there were other themes or issues that had been overlooked. Across all focus group sessions staff agreed with, and supported the findings from the analysis. No new themes were added, but the second theme 'Barriers' was retitled 'Information' and combined with the theme of Communication. It had originally emerged as an individual theme during the analysis as the interviews had sought to identify specific obstructions in the healthcare system that impacted upon the delivery of palliative care in the ED. During the feedback sessions it became apparent that this was not a clear distinction for staff as each theme demonstrated a different type of barrier to the delivery of palliative care.

The quotes were effective in demonstrating touch points, prompting discussion and debate. A number of staff shared their own experiences and only a few refrained from participation. Lack of participation seemed to correspond to the size of the groups and the clinical experience of the individual staff member.

### **4.7.5 Frame 5: Selection and discussion of improvement priorities by staff participants**

Frame 5 led staff on from discussion and agreement of the themes shown in Frame 4 to identifying which of the themes were their main priorities for improving palliative care in the ED. This was done by providing staff with a ranking sheet (Appendix 11) to list what they felt were the three most important themes for the ED from the eight listed. Staff were asked to rank the themes as priority areas for improvement with '1' as the most important, '2' as the second most important and '3' as the third most important. Some staff struggled with this as they felt some of the themes were of equal importance, and some staff did not complete the ranking sheet as per the guidance provided. This meant that when it came to compiling the ranking data to identify the three most important themes, the number of scores were compiled and do not equate to the number of staff in attendance (Table 8). Tables 8 and 9 shows the ranking with the scoring for the three selected improvement priorities highlighted in red.

Of the three themes selected as improvement priorities, 'Communication and Information' was viewed as the most important area for service improvement, with 'Systems and

Processes’ as the second priority, and ‘Time’ as the third. During the feedback sessions staff referred to the challenges around time limitation frequently, however, this was beyond the remit of the study and what it could feasibly impact upon. Therefore the decision was made with staff from the ED and the study supervisors to include the theme ranked fourth; ‘Training and Education’. The reason for including ‘Time’ as a theme in the feedback session was due to its ubiquity across the staff interviews. It was important to acknowledge their struggles to provide high quality palliative care in the ED against the four hour target. Even though it was not viable to include this theme as an improvement priority, developments in the themes selected would feed into time management, for example potential improvements in access to patient information.

Through observation and reflection of the interviews, non-participant observation and feedback sessions it had become evident that there was no consensus of what palliative care was, how it should be applied or who should be providing it. This raised the argument that improvement efforts in the three selected themes would be undermined by this lack of agreement, as well as indicating a lack of consistency in care provided to patients with palliative care needs and their carers. These observations were fed back to the PDN and subsequent discussions then led to the inclusion of a fourth priority area: ‘Palliative Care’ to support and enhance the improvement priorities selected by the staff.

The validity of including a theme that had not been ranked as high by the staff groups was questioned against the study methodology. Yet the methodology states that the role of facilitator/researcher is an inclusive and active one. The research process can be enhanced by the recognition of touch points which may have been overlooked by the staff, patients and carers through the processes of observation and reflection (Zuber-Skerritt and Perry, 2002, Donetto et al., 2014).

**Table 8: Staff ranking of improvement priorities**

Themes	Rank 1	Rank 2	Rank 3	Total
<b>Communication (&amp; Information):</b> Improving communications between ED staff, specialist palliative care teams and other specialities.	13	11	2	26
<b>Systems and Processes:</b> Making systems and processes in the ED, the wider Trust, and beyond the Trust more efficient and responsive to the needs of older patients with palliative care needs.	5	11	7	23
<b>Time:</b> Redesigning or reconfiguring ED and other services in ways that would allow more time to care for older patients with palliative care needs who attend the ED.	5	3	7	15
<b>Training and Education:</b> More formal training and education (in palliative or end of life care) during pre & post-registration training of staff.	2	4	6	12
<b>Barriers:</b> Improving awareness of how different professionals (ED staff, palliative care team, staff elsewhere in Trust, community health teams) can work together to provide palliative care for older people in the ED.	4	3	4	11
<b>Roles:</b> Clarifying the respective roles of patient, carers, ED staff, palliative care teams and community healthcare professionals in providing care to older people with palliative care needs who attend the ED.	2	2	6	10
<b>Palliative Care:</b> Improving ED staff understanding about how palliative care is defined, understood and thought about.	2	2	4	8
<b>Age:</b> Supporting all staff to view and think about older patients in the ED in the same way as other patients in terms of respecting and responding to their treatment choices and care.	3	1	2	6

Three types of data were recorded from the ranking sheets. First were the staff priorities (Figure 33); second were staff perceptions of what the patients and carers would consider the main improvement priorities for the provision of palliative care in the ED (Figure 34); and the third was a record of the comments and suggestions given by staff providing additional detail or potential solutions to improve the existing themes. The perceived patient-carer priorities had been extracted from the interview data where staff commented on patient and carer experiences. Staff perceptions of patient and carer needs were recorded to compare with those that were actually identified by patients and carers in the next Stage of the EBCD process (Chapter Six). These data were used to help shape the final improvement priorities in the co-design event presented in Chapter Seven and reveal how accurately staff understood the needs in the ED of older palliative patients and their carers.

**Table 9: Staff ranking of perceived patient and carer improvement priorities**

Themes	Rank 1	Rank 2	Rank 3	Totals
Lack of staff time to attend to their needs	8	9	8	25
Poor communication between ED and other services	12	6	5	23
Inefficient systems and processes	5	8	5	18
Low awareness amongst staff of available services	2	1	7	10
Little staff training and education (in palliative and end of life care)	1	4	3	8
Poor staff understanding of palliative care	2	3	1	6
Poor understanding of different staff roles (including specialist services)		2	4	6
Staff awareness of older patients	2		1	3

### **Discussion and application of the improvement priorities to the study and wider literature**

Following the selection by staff and the researcher, the four themes were termed Improvement Priorities. Of note, each of the four priorities mirror the challenges raised in the literature in Chapter Two. The following section reflects on these similarities and their implications for this thesis before moving on to Frame 6.

#### ***Improvement Priority: Palliative Care***

A major obstacle for palliative care in the ED is the well documented lack of agreement, understanding and use of palliative and end of life care terminology by staff, and patients and carers (Fallon and Smyth, 2008, Hui et al., 2012). In the interviews staff reported often feeling unprepared and ill-equipped to provide care for terminally ill patients, as well as revealing different perspectives about what palliative care provision actually meant. In both the interviews and the literature review confusion lack of consistency over definitions and their clinical meaning was identified as a significant cause of miscommunication between staff, as well as between staff and family members (Heaston et al., 2006, Beckstrand et al., 2008, Smith et al., 2009, Grudzen et al., 2011b). These disparities in understanding of palliative care between staff, patients and carers at times resulted in confusion and delivery of inappropriate care (Heaston et al., 2006, Beckstrand et al., 2008).

The following two quotes demonstrate the different approaches taken by ED staff in response to palliative care patients. In the first quote the staff nurse was unclear about what palliative care delivery meant, and they viewed it as the absence of ‘doing something’. Conversely in the second quote the junior staff nurse demonstrates a much wider understanding of the intricacies of care needs of older palliative patients and what is required of their role. It can

be inferred from these differences in approach that there is a lack of consistency in palliative care delivery in the ED.

*'... , how I see palliative care, but...maybe I'm wrong... I'm not doing anything. I'm kind of backing away. I'm doing less, if you see what I mean. So I don't see that as kind of me doing something...I'd never really thought about it, the fact that me, with the withdrawal side, is part of palliative care...I don't tend to focus on the end of life bit. I tend to focus on what we can do...about keeping them comfortable, and pain relief, and then support to the family...Because my A& E brain says I need to be doing something...'*

(Staff Nurse, Interview 7)

*'...So patients who have been diagnosed with a possibly terminal condition...Don't know quite how long it might be, but somebody who's not necessarily going to go for active treatment...but they've come in with a general deterioration...for symptom control, and not coping at home... their families have become very concerned...Other instances we've had patients who've been palliative at home, elderly...living on their own, the neighbour has not heard from them for very long, and so they phoned an ambulance, and that automatically brought them straight into hospital, and it's been very clear when they've got there that they're actually in the process of dying...And so it's not appropriate to send them straight home...they may have wanted to, but they've had to come into hospital...it was all just about trying to keep them comfortable in a sort of quiet-ish environment as possible...'*

(Junior Staff Nurse, Interview 9)

The following third quote continues the evidence of misunderstanding of the definition of palliative care, not only by the staff, but also by the patients and carers:

*'...if you're known to palliative care services the concept of death should have been discussed. But it's not. Or the patients deny, or the relatives deny it. Some seem to even not really know what palliative care means and what they should be getting from the service. Some don't seem to know that the cancer treatment not working and being then referred to palliative care and doctors saying there's nothing more they can do still means they could die. You know, there seems to be some that just seem to be so not in the, in the room and I don't know if it's because we're bad communicators, whether or not the patient's just so much in denial. We'll never know from where we see, but they certainly tell us, 'We were never told.' And you sort of go,*

*'Okay, you know, maybe they weren't. Is it, is it possible?'...you just don't know and you don't want to accuse all patients and relatives of being wrong, but jeez there's a lot of patients that seem to claim they were never told they could die from this...'*

(ED consultant, Interview 12)

### ***Improvement Priority: Communication and Information***

Underpinning many experiences in the interviews as well as the literature base, either positively or negatively, were factors related to communication and information, particularly at the community-ED interface (Smith et al., 2009). The following quotes exemplify some of the challenges faced by staff with their own suggestions for possible solutions:

*'...so sometimes communication... unless the GP writes the letter and is sure to give it to them, you could just end up with a patient coming in with the ambulance letter and nothing else. And depending on how good the GP is...they just come in without anything. Which is much less helpful than if you've got their background, history and what their GP's assessment was, or a letter saying, "I think this patient needs admission." Then it makes your job... well time wise, much less because that was their aim, to admit the person to hospital rather than have an assessment and to send them home...'*

(Interview 2, Junior Registrar)

*'...More access to GP information (24 hours) as they have every bit of information regarding patients...'*

(ED nurse response in feedback session)

*'...Clear palliative care plans between community and A&E (i.e. ceiling of care/DNAR forms)...'*

(ED nurse response in feedback session)

### ***Improvement Priority: Systems and Processes***

In both the literature and this research, ED staff raised the issue of concerns about the ED systems, and the safety and appropriateness of the environment and for this vulnerable patient group (Heaston et al., 2006, Beckstrand et al., 2008, Smith et al., 2009, Grudzen et al., 2011b). Staff identified the time limitations inherent with the ED system, and workload burdens as barriers that prevented them from giving palliative care patients the attention they required (Heaston et al., 2006, Beckstrand et al., 2008, Grudzen et al., 2011b). Within the interviews the internal systems and process for working in the ED were often found to be in

conflict with external services such as GP surgeries and care homes. In this way the systems and processes acted as a barrier to the provision and integration of palliative care in the ED (Smith et al., 2009, Grudzen et al., 2011b). Due to the current model of care in the ED, staff in the interviews and feedback sessions held mixed opinions on the integration of palliative care in the ED which would require developing new systems and refining existing ones:

*'...it kind of happens all the time. People come in and they obviously have long term sickness, and you think, 'Oh, you know, this person's not going to make it this time.' But we go through the motions anyway...No, I don't think it's right. I don't think it's good for the patient, but with the litigation that goes on you can't really afford to be withdrawing on the patients who are coming in who are sick...'*

(Interview 7, ED Senior Nurse)

*'...It is difficult in my view because what we consider emergency may be different from what a family and carers are considering in the community...It's different when I'm here with all the equipment monitoring, the nurses, and other specialty doctors surrounding me. I've got no hesitation to see anybody. That's what I do every day. If they feel they need to see a doctor I'm available to, to see them, reassure them, or treat them. Or, I help them to cope better. Especially this kind of vulnerable group of patients where they are not only stressed because of the disease, the diagnosis and outcome, or expected outcome, but also they're vulnerable because they're elderly and losing the other half for example, of you, your soul mate for 15 years has got major, major effect on their mental status...'*

(Interview 10, ED Consultant)

With the selection of 'Systems and Processes' as an improvement priority came suggestions for how these could be altered to respond to the needs of older palliative patients and their carers:

*'...The patient needs one book (not folder) with all the info including their Not For Resuscitation paperwork in it with bits the patient has written for their own wishes, drug history, past medical history - also let the London Ambulance Service know to look for this book...'*

(ED nurse response in feedback session)



*'...To allow palliative care to happen in A&E - better communication between community, A&E, the patients and relatives - a plan in place if deteriorates...'*

(ED nurse response in feedback session)

*'...Direct admissions without coming through A&E with plans for admissions made in community...'*

(ED nurse response in feedback session)

### ***Improvement Priority: Training and Education***

A lack of palliative and end of life care training and education was cited by staff in the literature and interviews as a significant reason for resisting or struggling with the provision of care of the dying in the ED (Payne et al., 1998, Beckstrand et al., 2008, Grudzen et al., 2011b). Some staff expressed concerns that they were ill-equipped to manage the emotional responsibilities associated with the provision of palliative care (Grudzen et al., 2011b). It may also be why one of the articles observed that many ED staff may actually be demonstrating important skills needed in palliative care but not identifying them as such, for example reassurance, kindness and contacting families (Carunchio, 2011).

In both the interviews and feedback sessions staff were quick to identify some of the specific challenges they face in relation to palliative care training and education in the ED:

*'...I have this quote that A&E staff are the jack of all trades and the master of none...because we don't know about one specialty we know about hundreds... So it's going in, very quickly determining what's wrong with somebody... it's a really good skill but, because there are so many different specialities that come in and you'll highlight this, input on this and then...time will pass and we'll need to go back to this again because people have forgotten about this or need a bit of reminders...'*

(ED Senior Nurse, Interview 8)

*'...it's not something I think we teach very well...I think when we do talk about these things... unfortunately we often do it at almost the opposite end of the hospital to the A&E, and admissions, we normally seem to think about these things towards discharge, or patients who've been in for a long time...so I think there is a lack of recognition of patients for whom...doing everything is not necessarily what they need, and doing what they need is probably the better way of doing it...but if there's nothing you can think of that's reversible, maybe not doing some things...I think we're not*

*good at teaching that, we're not good at pulling those skills that we've taught somebody on the wards, down to the A&E department and putting it into that context...*' (ED Registrar, Interview 14)

To conclude this section, one particular comment made in an interview encapsulated why all four of the themes were important and selected as improvement priorities:

*'... I suppose it's [palliative care] lacking because they're the sort of people that just need a bit more, and it's a stressful time for them. We don't have enough information about their care in the past, and it's a bit like cardiac arrest...You need to make instant decisions. You can't leave people hanging around for hours. And the emotional side of it is stressful, you've got families who are upset, patients, probably deteriorating at that point, and in your heart you want to make it a good death if they are going to go at that point, or you want to make it a good experience and get them to the right place. So it's an important time for them, but don't have any training on that. You have your life support training, but you don't have any death support training...'* (Junior ED nurse, Interview 9)

#### **4.7.6 Frame 6: Re-presenting the improvement priorities for the co-design event**

Frame 6 emerged at the end of the data analysis process with patients and carers. Although discussed further in Chapter Six it is presented here as it was the final iteration of the staff data. The themes selected for improvement priorities by staff, patients and carers were closely linked and demonstrated a shared experience affected by the same issues. In preparation for the co-design event (Chapter Seven), the staff analysis was revisited and the phrasing of the four improvement priorities was rewritten into more accessible language. This was important as many of the collaborators did not have a healthcare background and so terms would not have held the meaning that they instinctively held for staff. The goal was to present the priorities as part of the narrative that could be easily accessed and understood by people from different contexts (Bevan et al., 2007). Table 10 shows how the improvement priorities were reorganised and rephrased to present a cogent story of the staff experience of palliative care provision in the ED.

**Table 10: Re-presenting the staff improvement priorities**

Themes	Finding the story
Systems and Process	Helping patients and carers find their way
Communication and Information	Being informed and informing patients and carers
Palliative Care	Seeing the person in the patient
Training and Education	Expectations of the care we can give

The parallels between the experiences are discussed further in Chapter Seven. In the following section the narrative reflects on the additional fact finding exercises during the undertaking of Stage 2 of the EBCD process. Although much interesting information was obtained, to maintain the narrative story of the thesis only the salient points are documented here as they relate to the improvement priorities.

## **4.8 Reflection on fact finding exercises**

### **Coder and palliative care consultant interviews**

The interviews explored coding, the recognition of palliative care patients, and how these might impact on the ED. As it transpired, the actual coding of palliative care was not directly linked to the ED but the debate between specialists relating to its application emphasised how confusing it would be to generalist practitioners, particularly ED staff. The palliative consultant summed up the problem in the following way:

*‘...The challenge is that palliative care should be done by all, but also terms mean different things and so seeing the code ‘palliative’ might mean something to people and not to others, or that we don’t or do give them things. There is a huge possibility for misuse...the term ‘palliative’ it’s a hornet’s nest because people don’t really know. It means such different things to different people...’*

This led into a discussion about the ways that staff in the ED could identify palliative care patients and contact the palliative care team for help. There were existing IT platforms containing specific information about palliative care patients within GSTT that ED staff did not have access to, although this issue was being explored for a solution. There were also no flags on the main electronic patient records (EPR) system to indicate if a patient was known to the palliative care team or other palliative care network, such as the Gold Standards

Framework. The consultant mentioned an EPR referral form tailored for use by ED staff to refer for palliative care input that had been available for a year but never used. Feeding this back to the ED staff revealed that most were unaware of its existence and those that were aware, were unsure of when to use it.

Poor communication and sharing of information between the community and hospital were also recognised as barriers for patients being triaged to the right location or receiving the appropriate care. The perception of the palliative care consultant was that as the ED only sees patients for four hours, they would have little to do with coding, and little need for palliative care training and education. Therefore, although a series of palliative and end of life e-learning modules had been developed, they contained no ED scenarios. Chapters Seven and Eight explore how this perception changed over the course of the research and the gradual increased involvement of the palliative care team in the ED.

### **Observations of Post-Take Ward Rounds (PTWR)**

The PTWRs were a valuable way of gaining insight into the impact of the ED on palliative care patients. Interestingly, the challenges with defining palliative care emerged again. The perception of the medical consultant leading the team was that it was more to do with the end of life, rather than a supportive mechanism within the trajectory of a terminal condition. There seemed to be a general reluctance to discuss or initiate palliative care services or conversations on the rounds unless stated in the notes, even where patients appeared to be approaching the end of life. When questioned, the consultant said he assumed these issues would be addressed by other clinicians at some point later in the patient's care.

While the fine detail of the care provided in the ED was generally not discussed, the impact on palliative care by the ED appeared to be in the processes, referrals or links to other teams that were started and documented in the patient notes. These appeared to shape the discussions and decisions of future treatment set by the staff on the PTWR. Two case studies that demonstrate this influence of the ED on patient care are shown in Figure 26. The extract concludes with the research observation made at the end of the rounds.

**Figure 26: Extract from the PTWR comparing case management of acutely unwell patients**

### **Case Study A**

#### **At home**

95 year old gentleman admitted from home with extensive bruising to upper quadrant; carers come three times a day. The day of admission the carers noted widespread bruising and were concerned there had been elder abuse but the cause for the bruising is unknown. The gentleman appears confused, frail and weak. Past medical history includes COPD, aortic stenosis, pneumonia and numerous falls.

#### **In hospital**

The gentleman appeared weak and disorientated and was on oxygen to aid his breathing which was quite laboured. The ward staff had surrounded his bed with 'falls mats', raised the side bars and raised its height to counter and guard against falls. The notes were being used by the nursing team and I was therefore unable to trace back his care to the ED, but the decision was made on the PTWR to escalate care should he deteriorate, though he was not for CPR. There was no mention of palliative or supportive care, referrals or chasing these services to identify the support and care in place for this gentleman. I did not mention palliative care to the team to see if they raised it; no one did. This was quite surprising as his condition was similar, and slightly worse, than the lady discussed below who was known to a palliative care team.

### **Case Study B**

#### **Reason for admission and past medical history**

78 year old lady admitted with COPD deterioration, chest pain and shortness of breath from home. Past medical history includes CCF, proximal AF, end stage COPD, pleural effusions, and high cholesterol. She is cachexic, frail, has lower leg oedema and a grade 2 sacral wound. Has been self-caring at home but condition has been worsening.

#### **The hospital journey**

The front sheet of the patient's notes from the ED records the patient as being 'palliative' and mentions the LCP. However this is not mentioned again throughout the notes. The patient was moved from the ED to the acute admissions unit where a discussion was had with the patient regarding her resuscitation status. This was subsequently recorded as DNAR. During the PTWR the team discussed the medical management of the patient which included fluid management to counter the oedema. Though the patient was clerked and discussed as being end stage COPD, she was still for full treatment.

#### **Researcher reflections and observations**

I remained with the patient to gain consent to use her case study in this research and the consultant came back and told me there were palliative discussions occurring about her. However I was unable to find where these although it appeared that she was receiving palliative care in the community. I could not obtain confirmation that the hospital staff would be contacting this team to identify her treatment and care and any planned pathways. Even after reading her notes I was unable to determine quite why she was admitted or who had called the ambulance, and if this had been a breakdown in community support or an organised admission.

There was no reason for the patient to be on the LCP at this stage but the notes did not refer to it again. Among the PTWR team there was some mention of the term ‘palliative’ in regards to this lady even though it was slightly ambiguous as to what this would be. This lady was seen shortly after the gentleman and I was surprised that as their cases were fairly similar in terms of disease and disease progression, there was no mention of palliative care for him.

It appears that unless someone is actively dying or they already have ‘palliative’ written in the notes, there are no common triggers to calming down active treatment or discussing the possibility of supportive care with these patients. This is very much an assumption based on what I observed and discussed with the staff on the PTWR, and is not a criticism or comment that it is wrong, but it seemed that management of these older, very sick people is a case of ‘treat until the end’.

## **4.9 Critical reflection**

The conduct of Stages 1 and 2 of the EBCD process was both exciting and challenging to undertake. The initial engagement with staff and gatekeepers at the ED was quite slow and I was concerned that I would not be able to conduct the full study beyond the staff interviews. The PDN was an ongoing supporter of the study and the new clinical lead had a positive impact on the progression of the study as they were more open to the research.

The recruitment process was also challenging, even when the recruitment route had been altered. The ED is a busy environment and approaching staff on duty to invite them to participate was initially quite intimidating and took time and tactfulness to navigate. The positive aspect of recruitment from within the department was the development of relationships with staff stemming from being a regular presence in the ED. Interactions were used to discuss the research and express that the work was not being undertaken away from their experiences, rather that this was an opportunity for them to express their opinions and have an active role in how care could be improved.

In the early part of Stages 1 and 2 my own opinions were quite autocratic, stemming from personal experience formally within the ED and the hospice, and from stories shared by patients and staff. Without realising it, I believed I knew what staff, patients and carers were going to say in the interviews. It was only as I actually began to undertake the data collection that I was challenged by how strongly my voice could be heard rather than the staff participants. Such an attitude was greatly at odds with the ontology and epistemology underpinning this thesis, which by its very nature needed to accommodate multiple perspectives emerging from a range of lived experiences, rather than the single-minded pursuit of one outcome to ‘fix’ a problem (Hockley et al., 2013b).

Reflecting on each transcript I learned where I needed to listen and probe into staff experiences more and how to be quiet so that their story could be told. This process increased my appreciation of the perspective of the insider who is actually living with the phenomenon under investigation. It was this appreciation that made me hesitant to accept any research priorities emerging from the literature that had not been developed in conjunction with those providing or receiving the actual care.

Undertaking the fifteen staff interviews required patience and a pragmatic attitude. On occasions staff would forget the interview or cancel at the last minute. Where this occurred the interview slot was offered to other staff members. In this way the interview location proved both beneficial as well as challenging. Staff seemed more likely to agree to the interviews if it did not impact on their off-duty or shift work, but the location was often quite noisy, and staff had to be responsive to the needs of the department over the needs of the research.

The five feedback sessions were significant not only for the response they evoked from staff, but also their impact on my own confidence and abilities as a researcher. Standing in front of groups of ED staff and sharing my understanding of their experiences was daunting, particularly in early sessions when I was uncertain of their reactions. As the sessions continued and staff were predominantly positive, my confidence in my understanding of their data increased. The challenges of the session timing, layout and group size have been raised, and I found the cycles of reflection particularly useful for maintaining a flexible approach to the sessions to elicit staff engagement. In addition the sessions gave me an opportunity to explain the project and the co-design event, inviting staff to continue their participation. I also made use of the sessions to inform staff about the upcoming international fieldwork in New York to identify any specific practice that they would like me to explore (Chapter Five). Encouragingly, many staff were keen to hear about the development of the work, the findings from the fieldtrip research, and to attend the co-design event.

Following each session I shared the outcomes with the PDN who later asked if I would teach a series of sessions on palliative care at the next round of staff development days. She was happy for the content to be drawn from this thesis and used as part of the EBCD process. I told the palliative care team about the sessions and invited their input. Initially some team members were quite dismissive of the need for their input in the ED, however, as I shared the staff data with them, I observed their perspectives change and they became supporters of this

study. One or two members of the team attended each teaching session and made changes in practice as a direct result of this study. This is discussed further in Chapter Eight.

During this stage of the EBCD process I became aware of my developing role as a change agent. When questioned about their practice and opinions, several staff members reflected on their previous assumptions about palliative care and stated that they now felt differently. This was also noted in the feedback sessions. The impact of my presence in the department simply sharing or highlighting what staff were saying acted as trigger for several immediate changes in practice; again this is discussed further in Chapter Eight.

#### **4.10 Conclusion**

Stage 2 of the EBCD process provided deeper understanding and insight into the challenges faced by staff at St Thomas' ED. As the discussion in Frame 5 showed, much of their experiences resonated with the findings from the US literature. The exploration of the US literature and research into palliative care provision in the ED led to an international research fieldtrip to a geriatric-only ED at the Mount Sinai Hospital in New York. This international exchange of research findings and practice is explored in the following chapter.



## **CHAPTER FIVE: THE NEW YORK STORY**

### **(International development to the study at a Geriatric Emergency Room in Mount Sinai Hospital, New York)**

#### **5.1 Introduction**

The previous chapter demonstrated that the experiences shared by staff in this research shared marked similarities with those from the literature review in Chapter Two. As the staff participants began to identify experiences and challenges that reflected those of US staff, the supervisors of the study suggested that a valuable expansion to the research would be a closer examination of the most substantial responses emerging from the US. As stated in earlier chapters, one of the benefits of AR/EBCD is the flexibility of the design (Fisher and Phelps, 2006). Therefore the undertaking of a month long exploratory fieldtrip was a feasible and exciting developmental opportunity.

The aim of this fieldtrip was to develop translatable design principles that could enhance this study, and be of use to departmental redesign work at St Thomas' ED. The aim was met through two objectives:

1. To appraise and understand the data collected from the US site (Mount Sinai Hospital) as they related to the processes, decisions and work around planning for, implementing and maintaining a Geriatric ED.
2. To identify features or aspects that could be useful to the UK and this overall study, translating them into a tangible format of design principles that can be understood by clinicians, manager and patients.

'Design principles' (Romme and Damen, 2007) are the outcome of translating the tacit knowledge of organisational change agents (in this case the Geriatric ED staff and research team) into coherent and relevant principles (Plsek et al., 2007). These principles are then applied to and support the design of new settings and the redevelopment of existing settings (Plsek et al., 2007, Romme and Damen, 2007).

#### **5.2 Chapter overview**

The purpose of this chapter is to lead the narrative through the processes involved in the undertaking of the fieldtrip. This begins with the background, epidemiology and comparison

of UK and US healthcare systems, before presenting the practicalities of approaching the fieldtrip site; Mount Sinai Hospital. The narrative delivers the process of data collection and analysis which led to the development of a series of design principles that were presented back to key staff at St Thomas' ED to inform their own departmental redesign work. The narrative moves to a first person critical reflection of this process before leading the narrative back to the main story of this thesis, drawing the findings of the New York story into Stage 3 of the EBCD process: 'the patient and carer story'.

In practical terms a large body of raw data was collected from a US healthcare setting, then through a sequence of analytical frames developed into a series of practical, valid and uncomplicated design principles that could be applied to St Thomas' ED (Plsek et al., 2007). The design principles were specifically focused on decision-making processes, key lessons learned from the process, challenges to changing practice, the experiences of the patients, carers and staff involved, and the rationale supporting the development of a new model of emergency care for older people.

## **5.3 Background and context**

### **5.3.1 Epidemiology**

Increasing numbers of older and palliative patients are accessing the ED in the UK, predominantly due to a growing population of older people who are living for longer, often with multiple co-morbidities and increasing healthcare needs. Similar challenges are faced in the US. The data presented below show information pertaining to both over 65s and over 75s. The lack of consistency in existing data sets and therefore in comparisons such as those drawn below is a limitation for older person research first acknowledged in Chapter One.

In the UK, between 1983 and 2008 the proportion of people aged 75 and above grew by a third, from 6% to 8%, equating to an extra 4.0 million people. By 2033 it is projected that there will be 7.2 million older people (National End of Life Care Intelligence Network, 2010). In the US between the years 2000 and 2010 the population aged 65 and above grew by 15%, from 35.0 million to 40.3 million, representing 13% of the total population. By 2030 it is projected that over 65s will account for one in five of the total population (Albert et al., 2013).

In both countries this older population is at greater risk of admission to the ED than younger groups due to factors such as social isolation and chronic disease (Hwang and Morrison,

2007, Birns and Beaumont, 2009). Annually the UK has over two million unplanned admissions through the ED by people aged 65 and above, who account for 68% of emergency bed days (Imison et al., 2012). In the US older people account for 16-18% of ED visits (Sanon et al., 2014), with the number of admissions of older people annually estimated at 19.1 million (Albert et al., 2013). Data revealed that people aged 75 and older had the second highest admission rate of any group in the US (Grudzen et al., 2010).

Although it is not clear how many of these admissions are triggered by palliative care issues, it is recognised that many of these patients will have underlying palliative care needs (Grudzen et al., 2010). Additionally, use of the ED in the last year of life for all age groups is increasingly documented for both countries, with recognition that the final year may actually contain multiple ED admissions and extended hospital length of stay for the patient (Kreimer, 2010, The National End of Life Care Intelligence Network, 2012).

### **5.3.2 The UK and US healthcare systems**

Although facing similar demographic trends and healthcare challenges, the US and UK have different models of healthcare provision. This topic is a complex one but in summary, the UK has the National Health Service (NHS), a tax-funded, centrally operated model that provides universal coverage for the population, while the US has historically used an entrepreneurial model in which healthcare coverage is purchased through private health insurers by an individual or employers (Mcclintock and Liberman, 2007). There are therefore fundamental differences in how the public access healthcare and the models of healthcare provision that run within them. However, in both countries, healthcare systems have a degree of fluidity and are influenced by the prevailing government.

In the UK certain services are being privatised and healthcare is increasingly being viewed as a market place (Pym, 2014), while in the US recent introduction of ‘Obamacare’ in 2014 aimed to regulate health insurers (U.S. Department of Health and Human Services, 2015). Under the US Medicare system certain populations, including those aged 65 and above, are eligible for free healthcare according to various criteria, such as citizenship (Centers for Medicare & Medicaid Services, 2015). Based on these differences, a key consideration for this fieldtrip was the potential to develop broad design principles that could legitimately and safely be transferred from the US entrepreneurial model to the UK’s NHS to influence service improvement efforts in the field of palliative care in the ED. To assist with this

process, previous work exploring practical methods for extracting design principles from practice were drawn upon, these are discussed further later in the chapter (Plsek et al., 2007).

### **5.3.3 The evidence base**

The UK staff experience data generated in Stage 2 revealed striking similarities in the cause of barriers to the provision of palliative care in the ED to those referenced in the US literature. This is not unexpected as, despite the different healthcare systems outlined above, the models of emergency care are similar in the US and UK. Both systems of emergency medicine were established during the 1940s to the 1970s, and were designed to be a specialty focused on resuscitation, stabilisation and transfer to the most appropriate place of care for rehabilitation and recovery (Sakr and Wardrope, 2000, The American College of Osteopathic Emergency Physicians, 2011). Questions around the suitability of this model of care to meet the needs of the present day user population are aimed at both systems (Kenen, 2010, Couiliota et al., 2012). It is therefore perhaps unsurprising that staff within both ED systems report common challenges in the provision of palliative care in general, as well as specifically for older people.

In addition to the experiential similarities, the literature review found different US-based improvements in palliative care delivery for older people in the ED. Two papers which discuss reinventing parts of the ED to cater solely for older or palliative care patients were of particular interest (Hwang and Morrison, 2007, Grudzen et al., 2011a). In 2012 a press release in The New York Times announced that Mount Sinai Hospital in Manhattan, New York had opened a geriatric-only emergency room (Hartocollis, 2012). Prompted by the study supervisors to investigate the possibility of visiting and observing the department, it transpired that the ED was staffed and supported by several of the clinicians cited in this chapter, many of whom are leading the field in the development of palliative care provision and care of older people in the ED (Hwang and Morrison, 2007, Grudzen et al., 2010, Quest et al., 2011). The opportunity to meet and observe these experts in practice as they developed new models of ED redesign increased the value and potential learning of the fieldtrip.

## **5.4 Practicalities**

To carry out the fieldtrip there were three areas to consider. The first was to approach the staff at the Geriatric-ED to see if the visit was possible. The second consideration was

funding for the work. As the fieldtrip was developed after the study had commenced, the funding studentship did not contain the additional monies needed to provide for this work. Thirdly were the ethical matters, such as approval from the US site to conduct the research for the purpose it was intended; these are dealt with in the following section.

#### 5.4.1 Identifying and approaching the site

The fieldtrip was based at the geriatric emergency department at Mount Sinai hospital in Manhattan, New York. As with GSTT, Mount Sinai serves a diverse demographic and receives high numbers of patient visits annually ( Table 11).

**Table 11: Annual ED use by older people at GSTT and Mount Sinai**

	<b>Guy's and St Thomas' Hospital</b>	<b>Mount Sinai</b>
<b>Annual ED visits in 2011-2</b>	171,500 patient visits	92,485 patient visits
<b>Source</b>	(Guy's and St Thomas' Nhs Foundation Trust, 2012)	(Health Hospitals, 2013)
<b>Percentage of visits by those aged 65 and older.</b>	11.7%	16-18%
<b>Source</b>	(Beynon et al., 2011)	(Sanon et al., 2014)

A second senior-only ED was identified within the US (Holy Cross Health, 2015) but the department was in a process of restructuring its services and a visit was not possible.

Initial contact with Mount Sinai was made via an e-mail to the team of specialist clinicians, managers and researchers who led on the development of the Geriatric ED. The group are called the 'Geriatric Emergency Department Innovations in care through Workforce Informatics and Structural Enhancements' (GEDI WISE). They were awarded a \$12 million Healthcare Innovations grant by the Centers for Medicare and Medicaid Services (CMS) to develop their care of older people in the ED over three years. Much of the fieldtrip was spent with members of this group, in and out of the clinical setting.

The Geriatric ED opened in February 2012. All innovations and procedures used in the department were based on empirical evidence of positive outcomes in patient satisfaction rates, reduced return and readmission rates, and improved screening for inappropriate medications (Innovations Exchange, 2013). Between 2012 and 2013 specialist staff were recruited, changes in practice implemented, and outcomes data gathered within an on-going process of review. The work was still in progress at the time of writing this thesis (March

2015) and outcomes data have not yet been published. In addition, during the time of the visit (February-March 2013), the ED was functioning under increased pressure due to the effects of Hurricane Sandy at the end of 2012. The usual intake to the ED was significantly increased as storm damage had forced two other local EDs within Manhattan to close for renovations.

#### **5.4.2 The setting**

The Geriatric ED is a fourteen-bed unit located next to the main ED. It is a uniquely functioning environment containing a number of special features designed to improve the experience of the target demographic (those aged 65+). These special features are discussed below.

#### **5.4.3 Funding**

Funding for the fieldtrip was sought and granted by a travel scholarship from the Florence Nightingale Foundation (FNF) through The General Nursing Council for England and Wales. A report of the fieldtrip was written and submitted to the funding bodies (Blackwell, 2013).

#### **5.4.4 Ethical approval**

A protocol for the fieldtrip was written and ethical approval sought from the Institutional Review Board (IRB) at Mount Sinai. On the advice of research staff at the hospital, the data collection activities excluded gathering or documenting identifiable human data. It was agreed that aims of the fieldtrip could be met through contextual and fact-based information regarding the processes and use of resources or pathways, and informal opportunistic interviews with staff, patients and carers. As no identifiable human data were to be collected the IRB reviewed the protocol and responded that it did not require ethical approval. However, to undertake the research according the ethical research statutes in the US, specifically the Belmont Report (Department of Health Education and Welfare, 1979), and the Health Insurance Portability and Accountability Act (HIPAA) (U.S. Department of Health and Human Services, 1996), online training in ethical principles and governance was completed to gain certification from the Collaborative Institutional Training Initiative (CITI) (Collaborative Institutional Training Initiative, 2012).

### **5.5 Data collection**

In keeping with the need for a clear audit trail within an AR project (Green and Thorogood, 2009), the following section explains the methods, management and organisation of the data collection process. Although the undertaking of the research was an exciting and interesting process, it was important to keep the data collection focused on material that related to the

development of the Geriatric ED that could potentially inform new design principles for the UK study. To this end the rationale for each type of data collected is provided. The section concludes with a description of the Geriatric-ED and its special features to provide additional information and context for the analysis.

### 5.5.1 Data collection methods and organisation

The process of data collection was carried out over one month and comprised over 140 hours spent in and around the department, gathering qualitative data from the clinical setting, staff training sessions and GEDI WISE strategic meetings. As with the data collection and analysis in Chapter Four, the principles of grounded theory were utilised so that the inquiry was iterative and open, gathering data and refining the search process as required based on the emerging findings (Holloway and Todres, 2007).

Data were mainly collected as field notes from non-participant observation and informal interviews; although on some occasions by invitation from the GEDI WISE team there was active participation in meetings. This involved sharing observations and progress on the fieldtrip, and discussing UK ED processes and challenges. The various methods of data collection and the rationale for their use are detailed in Table 12.

**Table 12: Data collection methods and sources**

<b>Data collection method</b>	<b>Source and rationale</b>
<b>Observation</b>	<ul style="list-style-type: none"> <li>• <b>Of clinical practice</b> – <i>for specific and general processes and procedures</i></li> <li>• <b>Staff interactions with each other</b> – <i>how did staff relate and communicate with other, e.g. tone, calmness, respect, frustration?</i></li> <li>• <b>Staff interactions with patient and carers</b> – <i>what elements of care were highlighted; how were patients and carers spoken to?</i></li> <li>• <b>Ward rounds in the ED and other settings</b> – <i>what aspects of patient care were highlighted; what members of the team were involved; were patients/carers included; were issues such as privacy and dignity automatically catered for?</i></li> <li>• <b>Staff training sessions</b> – <i>what aspects were considered important; how did staff respond; what level of complexity did the training cover?</i></li> <li>• <b>Meetings and a retreat day for all GEDI-WISE staff</b> – <i>how are the staff from three different hospitals, at different stages of project development, working together; how are challenges faced; how is learning and knowledge shared; what are the future priorities?</i></li> </ul>

<b>Informal interviews (documented as field notes; no audio recordings were made)</b>	<p>With:</p> <ul style="list-style-type: none"> <li>• <b>GEDI-WISE team members</b> – <i>what led to the opening of the Geriatric ED; what role do they play; what processes have occurred; what are the future plans; what challenges do they face; what successes have they had; what outcomes are they monitoring?</i></li> <li>• <b>Staff (main ED, Geriatric ED, other settings who interact with the Geriatric-ED)</b> – <i>what are the experiences of the Geriatric ED; what understanding do they have of palliative care; how do they feel about the Geriatric ED and other interventions; what level of involvements and training have they had in geriatric and palliative care?</i></li> <li>• <b>Patients</b> – <i>what are the experiences of the Geriatric ED; have they been in the main ED before; what interactions have they had with staff; how do they feel; what could improve their visit?</i></li> <li>• <b>Carers</b> – <i>what are their experiences of seeing a relative in the Geriatric ED; have they witnessed care in the main ED before; how have staff interacted with them, how do they feel, what could improve their experience?</i></li> </ul>
<b>Photographs</b>	<ul style="list-style-type: none"> <li>• <b>Of the Geriatric ED</b> – <i>to provide a visual image for UK patients, carers and ED staff to consider when developing changes in the UK ED; to provide a record and image for knowledge sharing within academia and clinical practice beyond this study.</i></li> </ul>
<b>Field notes</b>	<ul style="list-style-type: none"> <li>• <b>From interviews and observations</b> – <i>served as the first record of data collected in practice. Field notes were organised into groups (see below). Gathering data this way minimised potential ethical difficulties. Notes did not contain any human identifiers. Audio recordings were also avoided due to lack of privacy in a busy ED.</i></li> </ul>
<b>Audio notes</b>	<ul style="list-style-type: none"> <li>• <b>Recorded throughout the fieldtrip providing a summary of personal notes, reflections and experiences</b> – <i>these were a personal record that served to aid personal development and highlight any key areas that required further exploration. These are considered within the critical reflection at the conclusion of this chapter.</i></li> </ul>
<b>Resources</b>	<p><b>Hard copies and links for:</b></p> <ul style="list-style-type: none"> <li>• <b>Tools</b></li> <li>• <b>Pathways</b></li> <li>• <b>Publications</b></li> <li>• <i>Each resource was located either within the department or as an internet-based resource. They serve as an addendum to support or challenge care provision claims and observations.</i></li> </ul>

Data were gathered throughout the fieldtrip using the methods presented in Table 12 and documented as field notes within eight different groups. The groups helped to organise the wealth of raw data into categories to prepare for the analysis and development of translatable design principles. This grouping, referred to as Frame 1, is discussed further below in the analysis. The eight groups and the information gathered within them were:

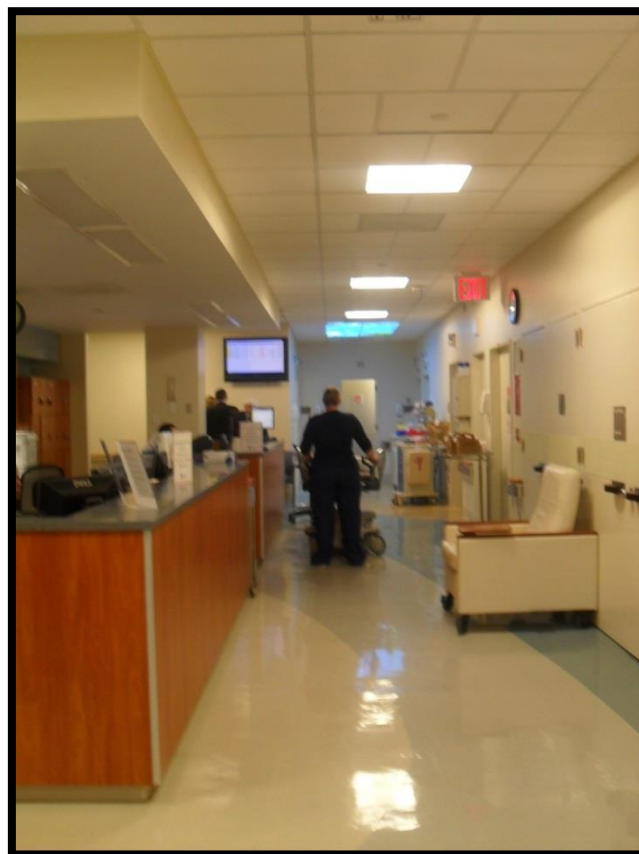


- **The Geriatric ED:** General information pertaining to the geriatric emergency department, and geriatric care in the ED in general. Examples include: facts and developmental information, training programmes, outcomes monitoring, links to other services or Geriatric EDs. This information was gathered from meetings, observations, the retreat day and other opportune moments of data collection.
- **Staff interviews:** Twenty one informal interviews and conversations were documented with staff from a variety of roles including: nurses, nursing technicians, physicians, specialist practitioners, social workers, volunteers and pharmacists. The data comprises personal opinions, quotes, overview of roles, and thoughts or information about the Geriatric ED.
- **Informal patient/carer interviews:** These data are limited due to the complexities of the patient group, meaning that many patients were too tired or unwell to engage with the interview. The data collected explored previous admissions, and opinions and experiences of the main and Geriatric-ED.
- **Specific resources:** This group served as a record for any resources identified during the period of data collection. This includes: national, State and local pathways, online resources and training, and department specific information related to palliative care and care of older people in the ED.
- **Case notes:** Thirteen patient cases were documented during the data collection period either directly from informal interviews or during periods of observation exploring palliative care in the main and Geriatric ED. The case notes, documented as part of the data collection and not referring to official medical notes, reported on staff-patient interactions, communication between services, changes in practice, and positive and negative experiences of care.
- **General and background information:** The data in this final group comprised information that did not directly relate to the day to day running of the Geriatric ED but was pertinent in some way. This includes: the inpatient palliative care unit at Mount Sinai, a visiting doctor's programme, and notes from a GEDI WISE retreat.
- **Observations of the main ED:** The Geriatric ED is a fourteen-bed unit located next to the main ED. It is a uniquely functioning environment containing a number of special features designed to improve the experience of the target demographic (those aged 65+). To appreciate the contrast between the two environments, some description of the main ED is required. The main ED is relatively small and quite

complicated to navigate, with very little room to manoeuvre beds. It is constantly busy, loud and bright. Patient trolley cubicles line the walls of the room, separated by partition curtains. During particularly busy times patient trolleys are placed head to foot, sometimes three-bed deep, with no partitions. If there is no space in the main ED patients will be placed in the corridors outside the main room. The ED is decorated in pale blue and grey with bright over-head lighting. There are a few seating areas for relatives but none at the bedside. The volume of people and movement meant it was not possible to take any photographs of this space.

- **Observations of the Geriatric ED:** Access to the Geriatric ED is via two large swing doors. The contrast to the main ED is stark: here the colours are light creams and beiges (Figure 27 ).

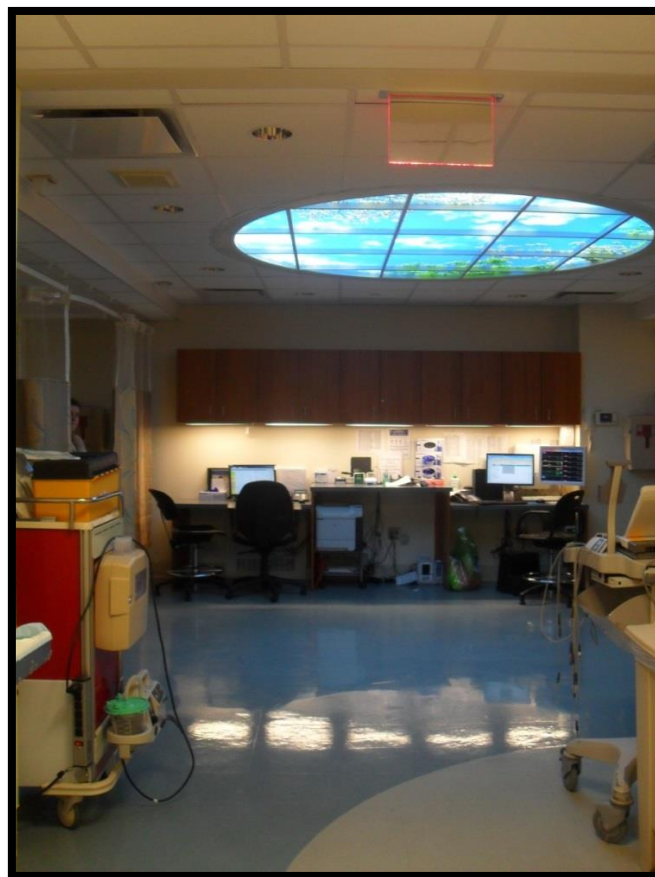
**Figure 27: The main nursing station and corridor of the Geriatric ED**



Two skylights are situated at each end of the ward, altering in brightness to reflect diurnal changes (Figure 28). Overhead lighting is softer. There is less noise, allowing people to communicate more calmly than in the main ED.

A volunteer scheme called the CARE programme (Care and Respect for the Elderly) supports ED practitioners and aims to reduce episodes of delirium and distress in older adults (Sanon et al., 2014). The volunteers, predominantly student nurses, work in shift patterns of four hours. Identified by their dark blue coats, similar to the white laboratory coats worn by the physicians, they are a smiling and friendly presence in the ED. The volunteers circulate the department, checking with ED staff the clinical and social situation of patients. Patients who would benefit from the volunteer service are approached and engaged in conversation. If required, patients are offered hearing aids, reading glasses and distraction therapies such as stress balls and brain games (Sanon et al., 2014).

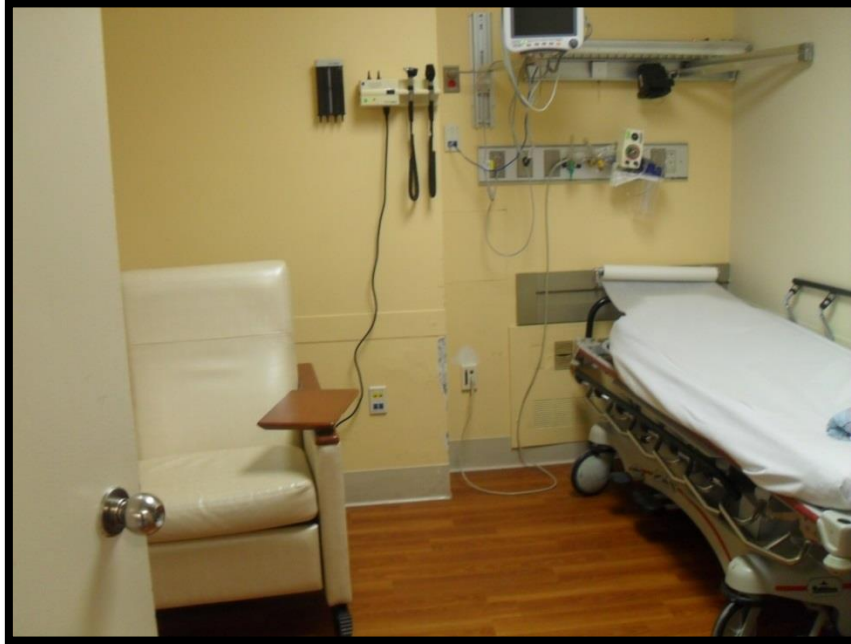
**Figure 28: Diurnal lighting**



To reduce noise, curtains are hung on plastic hooks to avoid metallic clattering. As with the main ED there are several comfortable seats for relatives along the walls, but also at each bedside. Spacious side rooms lead off from the main nursing station (Figures 29 and 30). At the far end of the ward is a small patient bay with two rows of trolleys (Figure 28). These are for more unwell patients who require closer monitoring. A smaller nursing station sits out

from the wall between these two rows. The trolleys are larger with thicker cushioning and each has a comfortable chair next to it.

**Figure 29: View of a patient room**



**Figure 30: View of a patient room (2)**



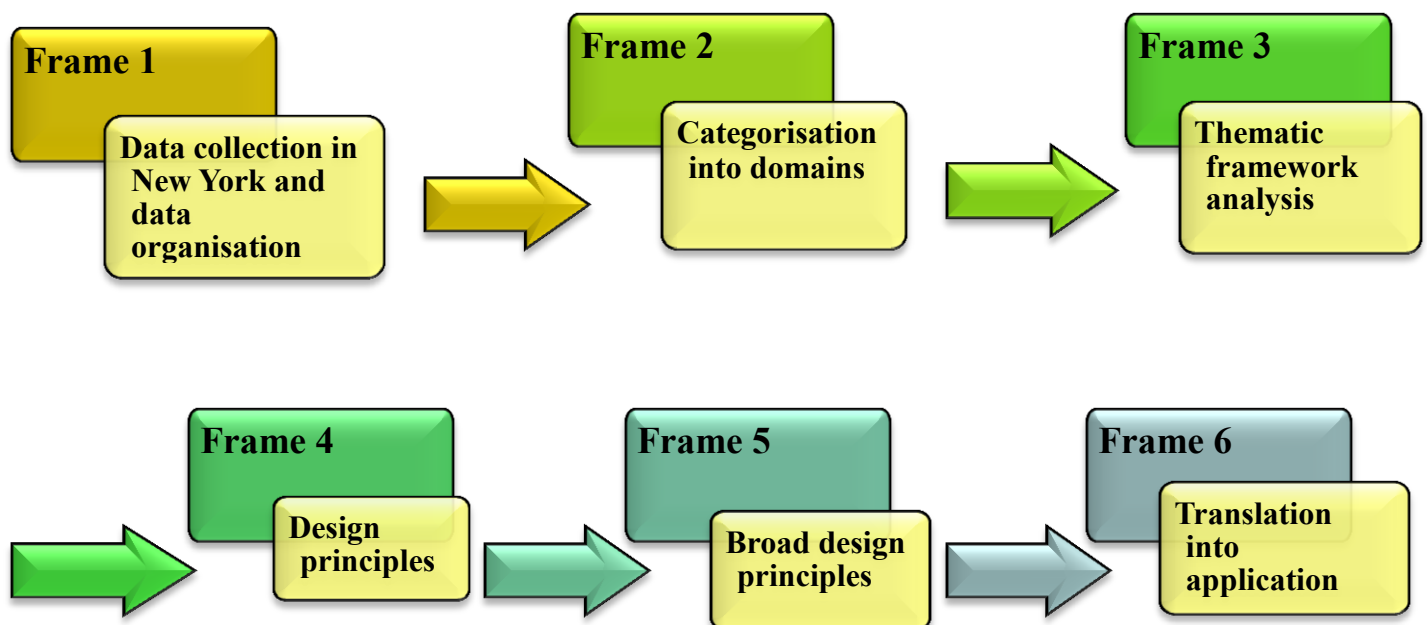
## 5.6 Data analysis

Having amassed a large volume of data, an analytical approach was developed to meet the aim of the fieldtrip. It had two objectives:

1. To appraise and understand the data as they related to the processes, decisions and work around planning for, implementing and maintaining the Geriatric ED.
2. To identify features or aspects that could be useful to the UK and this overall thesis, and translate them into a tangible format of design principles that can be understood by clinicians, managers and patients.

Moving the data from its raw format into the final design principles was done through six stages which are presented as individual frames of analysis (Figure 31). The iterative process of analysis was drawn from a grounded theory approach (Holloway and Todres, 2007) and the use of frames helped capture this synthesis of the data. The framing itself across this study, varies according to the data set; therefore the following six frames are different to those within Stage 2 that analysed the staff data.

**Figure 31: Frames of analysis**



Frames 1 to 5 deal with the organisation of the data, the thematic analysis and the development of design principles and broad design principles from the original data (see below). In Frame 4 a number of specific design principles were identified that related to

unique elements present in the Geriatric ED. In Frame 5 three broader design principles emerged through additional synthesis that encapsulated and summarised the meaning within the numerous design principles. It is at this point that the story of the Geriatric ED emerges, understood and presented through the process of analysis. Frame 6 presents the translation of the broad design principles into the final format that was presented back to St Thomas' ED and used to further the understanding the challenges found within this study (Appendix 12).

The theoretical approach for analysing these data remained grounded in the overarching methodology of EBCD, drawing on two papers analogous to this thesis. The first provided the thematic structure for the analysis: an EBCD study undertaken at the Hunter New England Health and Sydney South West Area Health Service Hospitals (Piper et al., 2010b). The work carried out by Piper and colleagues (2010) was designed to improve the experiences of patients, carers and staff in three EDs. The successful use of EBCD in the same clinical environment as this study recommended their approach to this analysis. Their analysis categorised the development design stages into the four phases. First was the diagnosis of problems, followed by the identification of the solution through a co-designed effort. Third was to implement the solution, and finally was the evaluation of the effectiveness of the solutions implemented.

Using this approach to deconstruct and understand the work of GEDI WISE team, the data were categorised thematically according to the stages of development of the Geriatric ED as follows:

- Challenges (found in the main ED that require changing to meet the needs of an older population)
- Solutions (to respond to the challenges)
- Strategies (to implement to solutions)
- Design principles (DP) (a descriptive principle encapsulating the solution and strategy)

These stages provided an early framework for categorising the data gathered from the Geriatric ED. Initially the same four terms were used to help break down and understand the processes undertaken by the GEDI WISE team in the development of the Geriatric ED: diagnosis, solution, implementation, evaluation. However, as the analysis progressed the

stages were renamed phrased into themes which better represented the work at Geriatric ED (See Frame 2 below):

The second paper explored practical methods for extracting explicit design rules from the tacit knowledge of healthcare staff working as change agents, which in the case of this fieldtrip was the GEDI WISE team (Plsek et al., 2007). This paper informed the development of the design principles and the final iteration of heuristic statements that were applied to the thesis (Appendix 12). Frame 6 contains an example of one of the broad design principles in its format as a heuristic statement that was provided to staff at St Thomas' ED as a suggestive guide to enhance their redevelopment of the department.

The analytical efforts concentrated on developing broad design principles rather than detailed rules (or guidelines). This was because, despite peer review from the GEDI WISE team, the analysis and construction of the design and broad design principles was carried out a solitary exercise. This is an important point for the EBCD methodology of this study, as innovations develop from collaboration between all users and providers of a service, not just the researcher (Pascal et al., 2013). Furthermore, the design principles drawn from the US work were not irrefutable, and were therefore submitted to staff, patient and carer participants during the co-design event for consideration and development of improvement strategies at St Thomas' ED. (Stage 4, see Chapter Seven).

The process of extracting design principles from the data was informed by the work of Plsek et al (2007) who provide four possible methods for this undertaking. As stated in Chapter Three, EBCD draws from three different bodies of knowledge, one of which is user centred design which the work of Plsek et al (2007) is grounded in. The four possible methods they suggest are:

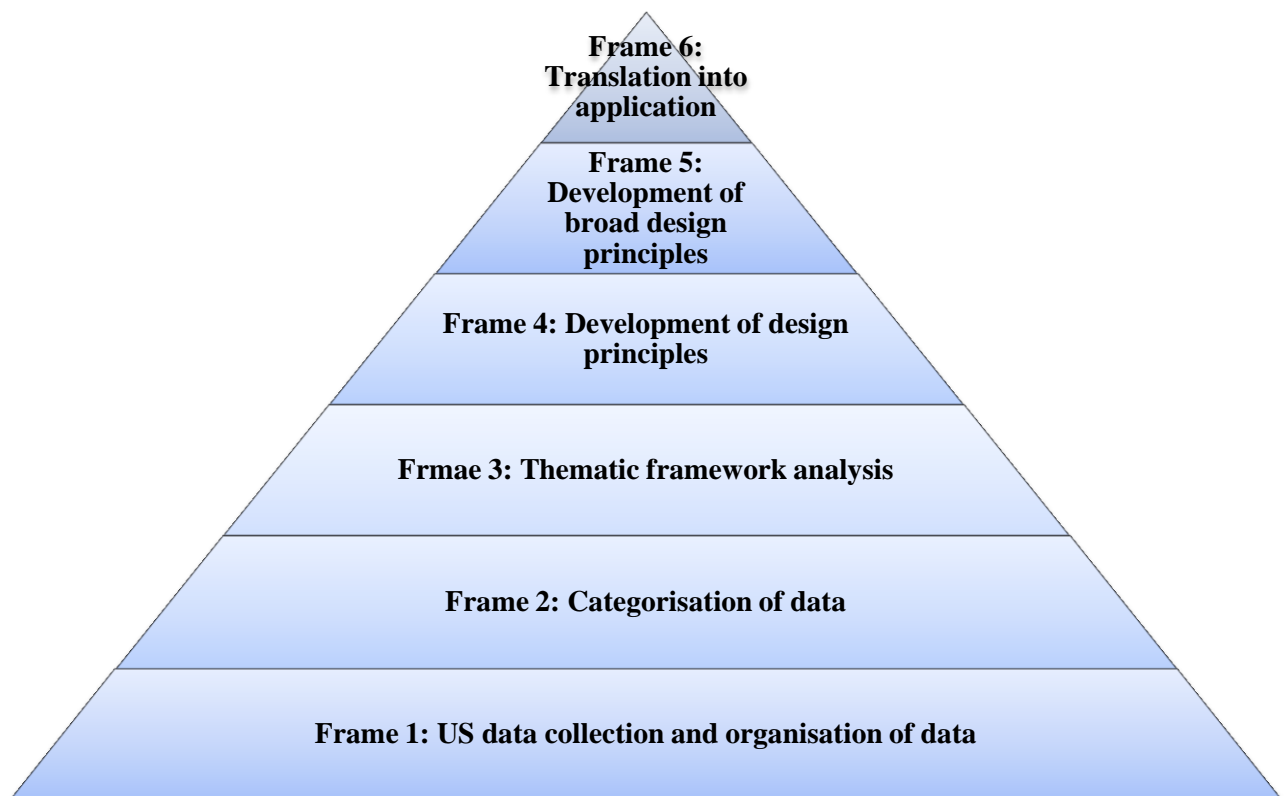
1. *Reviewing written documentation of change programs in order to extract design rules.*
2. *Convening groups of change experts and asking them to describe what they do, or see themselves as doing, in the form of design rules.*
3. *Listening to stories of change efforts told by change leaders, operational managers, and front-line staff and then extracting design rules off-line.*
4. *Posing hypothetical scenarios to those experienced in organizational change, asking them to "think aloud" about how they would approach the situation, and then extracting design rules off-line.*

(Plsek et al., 2007)

Of the four methods presented above the third was selected as the analytical approach for the Geriatric ED data analysis as it complemented the aims of the research in two ways. First, it drew on the insight and intuition of practitioners orchestrating change at the Geriatric ED, and second it reviewed the human insight captured through the interviews, observation and case studies, and identified the touch points that informed the design principles. This method also neatly brought the work back into line with the design processes of EBCD (Bate and Robert, 2007, Pascal et al., 2013). A further appeal of this third method was that it had previously been successfully used with UK ED practitioners discussing a US-UK quality improvement change programme (Plsek et al., 2007, Institute for Healthcare Improvement, 2010). This method was developed in response to challenges within the second method, whereby change agents, who were clinicians were able to share their practice but struggled to translate what they were doing into practical design terminology (Plsek et al., 2007).

To conclude the introduction to the data analysis, Figure 32 provides a visual representation of the stages of analysis, which synthesises the mass of raw data into clearly defined design principles.

**Figure 32: Visual representation of the synthesis of data**





### **5.6.1 Frames of analysis**

In this section the narrative presents the individual frames of analysis and movement of the data to its final presentation of the three broad design principles:

1. Communication
2. Preparation
3. Goal orientated on-going strategic review and development

One of the key features of the Geriatric-ED was the use of specialist staff to deliver care. They worked alongside generalist ED staff supporting care delivery in both the Geriatric and main ED. To help demonstrate the processes of analysis, the feature of specialist staff is used throughout as an example.

### **5.6.2 Frame 1: Organising the data**

This frame saw the mass of raw data collected during the fieldtrip organised into typologies under the following headings:

- The Geriatric ED
- Staff members interviewed and notes
- Patient and carer interviews and notes
- Specific resources
- Case notes
- General information/of interest/background information

Three additional typologies were used to collect additional information that was gathered during the trip and served as supporting documentation:

- Summary overview of each day
- Photographs
- Bibliography

### **5.6.3 Frame 2: Categorisation into domains**

Initial analysis of Frame 1 revealed that all data could be coded into different themes that sat within one or more of four domains concerning the need for, creation of, running and maintaining or experience of the Geriatric ED (Table 13). The four domains and the coded data contained within them are as follows:

- **Organisational Operations:** anything relating to the planning and development of the Geriatric ED.
- **Resources and Pathways:** anything relating to the provision of care to meet the needs of the older patient in the new Geriatric ED.
- **Staff Testimony and Experience:** anything relating to staff training for care of the older person, or the views and experiences of the staff working in the main ED and/or Geriatric ED.
- **Patient and Carer Experience:** anything related to the experience of being a patient or carer in the Geriatric ED and comparisons to the main ED.

‘Specialist staff’ was the named given to unique practitioners working within the ED, including social workers, nurse practitioners, geriatric-trained pharmacists and the trained CARE volunteers. The GEDI WISE team had identified different roles via a comprehensive review of the literature into improving care of older people, but this had not provided clear guidance on which roles were most beneficial or how to integrate them. All data referring to this group was coded as ‘specialist staff’ and found to impact across all the domains, as shown in Table 13 below. The broad influence of this group lent itself to be used as an exemplar of how the coded data were understood in the context of the four domains from this point forward. A second reason for including ‘specialist staff’ as the main exemplar is tied to the aim of the fieldtrip. This international work was designed to observe a new model of care and witness practice that could enhance and support palliative care provision for older people at St Thomas’ ED. At the time of conducting this fieldtrip (February 2013), none of volunteer or professional specialist staff listed were used within St Thomas’ ED. It was therefore of particular interest to see how they operated and if they appeared to improve care delivery.

As stated, the first domain ‘Organisational Operations’ deals with the initial development of the Geriatric ED; the new department was not just to be a separate physical space, but rather a unique new model for caring for older people which incorporated a structured multidisciplinary team. In this domain the specialist staff were found to have been brought in specifically to enhance the care provided in the Geriatric ED.

Table 13 shows how, in the domain ‘Resources and Pathways’ specialist staff were seen as intrinsic to encouraging and enabling collaboration across departments, and between the

hospital and community (a greater explanation is provided in Frame 6). They also helped to develop new assessment tools targeted to the needs of older people.

The domain ‘Staff Testimony and Experience’ included an exploration of the ED staff experience in the department. This found that specialist staff helped provide teaching informally in the clinical area, and formally in official training sessions targeting care of older people.

The predominantly observational data informing the domain ‘Patient and Carer Experience’ noted that specialist staff directly impacted on the experience of the older patients. One example was the pharmacists who reviewed patient medications to identify if the admission was influenced by the effects of polypharmacy. This process was often undertaken in communication with the patient’s primary physician and could lead to quicker discharges, rather than admissions.

**Table 13: Categorisation of data into themes within four domains**

<b>Organisation operations</b>	<b>Resources and pathways</b>	<b>Staff testimony and experience</b>	<b>Patient and carer experience</b>
<i>Theme</i> Identifying the need for a new department	<i>Theme</i> Collaborative working and specific human resources	<i>Theme</i> Provision of geriatric training	<i>Theme</i> Response to the new location
<i>Theme</i> Process of creating a new model of caring for older people	<i>Theme</i> Assessment pathway	<i>Theme</i> Response to the new Geriatric-ED	<i>Theme</i> Newly emerging needs of older people

#### **5.6.4 Frame 3: Thematic framework analysis**

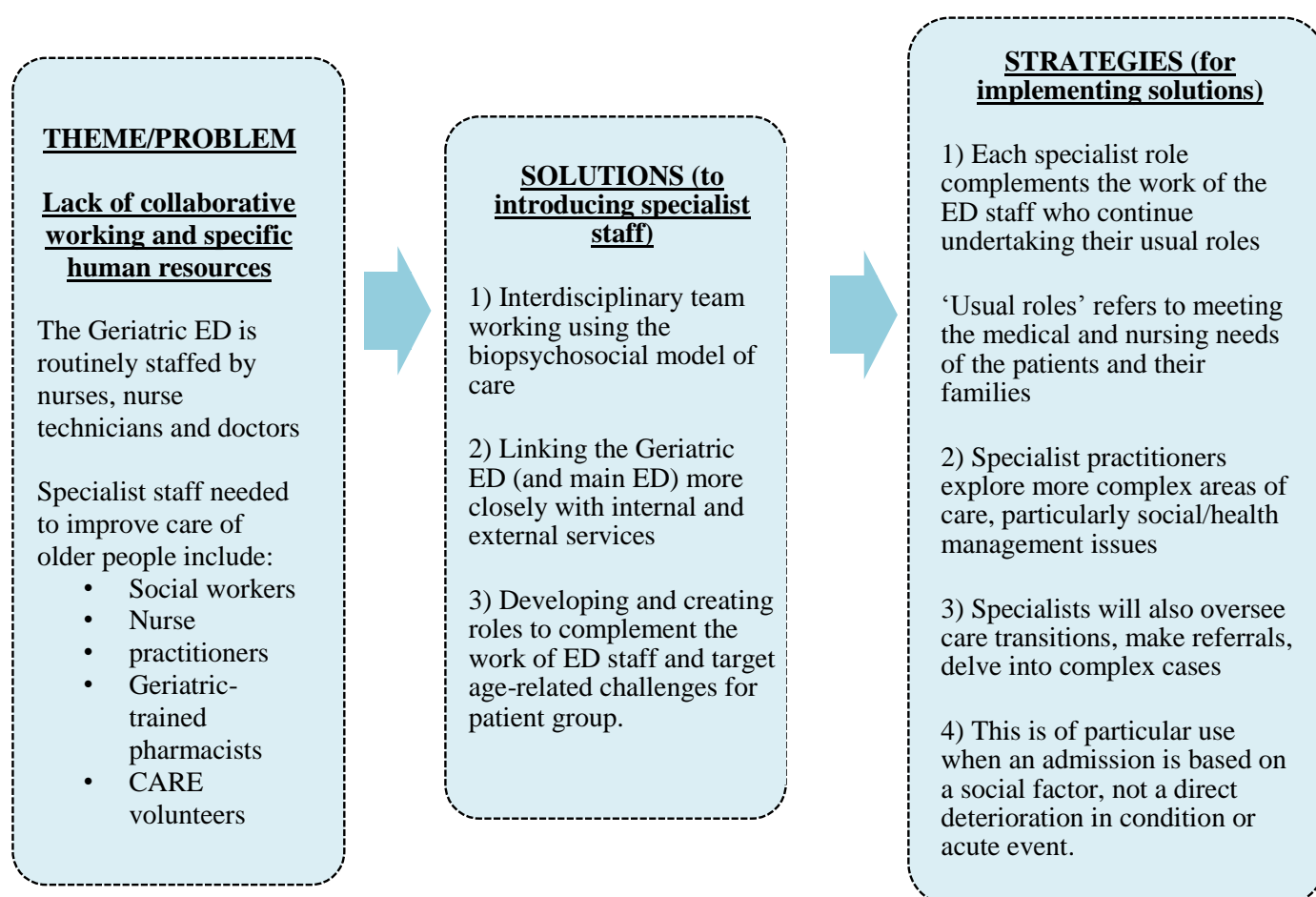
To summarise, the data had been organised into descriptive groups (Frame 1) and categorised into the domains and themes (Frame 2). Frame 3 continued the process of analysis, meeting the first objective of the data analysis ‘appraising and understanding the data informing the development and running of the Geriatric ED’. Frame 3 drew on the thematic framework discussed earlier which was developed within the Australian ED EBCD work (Piper et al., 2010b).

The purpose of analysis for Frame 3 (thematic framework analysis) was to critique the data from Frame 1 (data collection and organisation) within the themes and domains of Frame 2 (categorisation of data into domains). First it was important to identify what the challenges and problems were for the Geriatric ED. Next was to determine the solutions created by the

GEDI WISE team to respond to the challenges, and finally to capture the strategies used to apply the solutions that had helped to create, implement and maintain the Geriatric-ED.

The extract in Figure 33 explores one of the challenges highlighted within the domain ‘Resources and Pathways’ concerning the need to introduce specialist staff into the department. The first column in Figure 33 presents the theme of specific human resources and possible roles the GEDI WISE team identified. The second column lists solutions made by the GEDI WISE team to introduce and integrate these roles to enhance care delivery within the Geriatric ED. The third column contains the strategies that were used by the GEDI WISE team to implement the solutions. All of these data were gathered through interviews with, and observation of the specialist staff in practice.

**Figure 33: Example taken from the thematic framework analysis of the domain  
‘Resources and Pathways’**

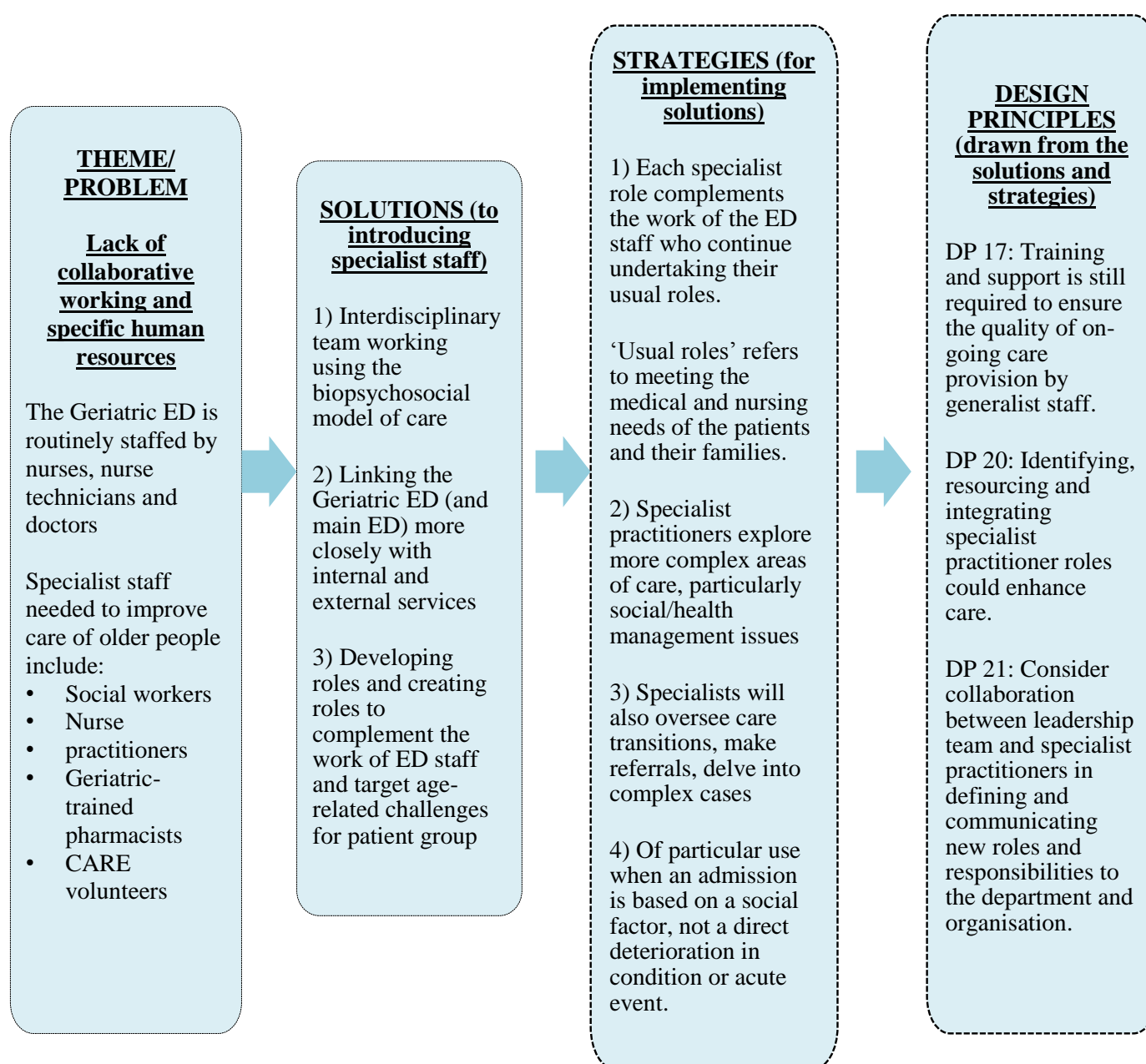


#### **5.6.5 Frame 4: Development of design principles**

The solutions and strategies identified in Frame 3 (thematic framework analysis) were further analysed to identify and extrapolate principles that underpinned the decisions made regarding the planning, running, maintenance and on-going development of the Geriatric ED. Thus in this frame the data were moved toward the second objective of the analysis ‘translation of the data into design principles to inform the work of the study’. In total, twenty three design principles (DPs) emerged from across the four domains. The full list of design principles is held within Appendix 13. The design principles were captured and listed as they emerged, rather than according to any specific structure or theme. Some also applied to more than one domain, for example, the use of specialist staff.

To continue with the example of specialist staff: Frame 3 (thematic framework analysis) emphasised why the GEDI WISE team introduced specialist staff into the Geriatric and main ED, how they could be integrated and what their potential impact was. The process of analysis in Frame 4 was to synthesise these findings into succinct design principles, presented in Figure 34. Here an additional column has been added which contains the three design principles that were created to summarise and communicate the information of the previously identified themes, solutions and strategies.

**Figure 34: Developing design principles drawn from the thematic framework analysis of the domain ‘Resources and Pathways**



DP 17 summarises the use of specialist staff in training and supporting generalist ED staff to provide ongoing high quality care. DP 20 was developed based on the information given throughout this analysis. It aimed to summarise the point that specialist staff were beneficial to a new model of care looking to improve care of older (and palliative) patients in the ED. Finally DP 21 recommends collaboration between managerial and specialist staff to define and communicate roles and responsibilities when introducing new staff to the department.

### 5.6.6 Frame 5: Broad design principles

During the development of the design principles in the previous frame, the analysis revisited the data set gathered from the Geriatric ED to reconsider the human experience and context for the design principles. As stated previously, this analysis drew on the principles of grounded theory and the iterative process of analysis. It became evident during the analysis in the previous frame, that the design principles were encapsulated by three underlying thematic principles, which then required an additional frame of analysis. The thematic principles, presented as broad design principles were communication, preparation and goal orientated on-going strategic review. These were essential to the development, planning, implementation, maintenance and continuing development of the Geriatric ED as discussed below. This frame presents the process of developing and understanding the broad design principles and how they encapsulate the various design principles.

A succinct summary statement explaining what was meant by each broad design principle was developed (Figure 35). Next the existing thematic framework was further developed to document where each design principle related to the broad design principles, supported by evidence from the data to provide context (Figure 36). Although at a surface level the broad design principles and design principles (full list in Appendices 12 and 13), may seem self-evident for designing a new model of care, as Plsek et al (2007) argue, the variations in results from organisational change suggests that ‘obvious’ principles are not always evident to those leading change. Therefore it was important to make each frame and principle explicit.

Figure 35 and Figure 36 provide an extract from this process. Here, the exemplar of specialist staff is continued. The single design principle (DP 20) advocates for the use of specialist staff for a specific purpose. The broad design principle then expands the capacity and role of specialist staff, incorporating them into a wider management structure which can be implemented to improve practice.

**Figure 35: Broad design principle: communication**

**Broad design principle:** Communication

**Summary statement:**

*Establish effective communication feedback cycles to empower all-level staff as change agents, to inform strategic review and implementation, and to disseminate information to the department and across the organisation.*

**Figure 36: Extract from DP 20 with supporting evidence from the data**

Design principle	Observation point
(DP 20) Identifying, resourcing and integrating specialist practitioner roles could enhance care.	Within the Geriatric ED I witnessed excellent interdisciplinary team working where specialist practitioners came alongside generalist staff to support their work and to meet complex patient and carer needs. This working benefited and improved patient, carer and staff experiences. However, in the ED where communication of new roles had not yet been fully disseminated, specialist staff reported finding it more challenging to use their skills and impact patient care.

Before moving on to the final frame of the data analysis, a critique of the supporting evidence for the developing of the broad design principles was undertaken. Continuing the narrative thread the critique presented below looks at the broad design principle ‘communication’ and the data relating to staffing and specialist staff that sit within it. The critique for the remaining broad design principles can be found in Appendix 14. Thirteen design principles related to different aspects of this broad design principle ‘communication’ and are listed in Figure 37.

**Figure 37: Design principles related to the broad design principle ‘communication’**

<p>(DP 4): Support on-going strategic review, consider maintaining a dedicated leadership team to oversee all projects, communicating with and supporting all levels of staff (use of cyclical feedback systems).</p> <p>(DP 6): Developing a cyclical system of feedback may enable staff and departmental needs to be effectively monitored, for example what are the needs, have they changed, are interventions proving effective?</p> <p>(DP7): Retain flexibility for adapting specialist roles, taking account of feedback.</p> <p>(DP 9): Develop communication systems within the department as well as across services in order to increase understanding of new roles and responsibilities, for example e-mail or meetings.</p> <p>(DP 10): Establish an on-going programme of feedback and review in order to ensure continuous improvement in the care of older people in the ED.</p> <p>(DP 13): Development of a model of care may be enhanced by identifying wider care needs of older patients in the ED.</p> <p>(DP 14): Systematically consider the following aspects of care delivery: staffing, environment, procedures.</p> <p>(DP 16): Working with other organisations may help identify best practice and establish a minimum data set for benchmarking good shared learning.</p> <p>(DP 19): Identify knowledge and skill gaps of generalist ED staff in order to provide tailored training.</p> <p>(DP 20): Identifying, resourcing and integrating specialist practitioner roles could enhance care.</p> <p>(DP 21): Consider collaboration between leadership team and specialist practitioners in defining and communicating new roles and responsibilities to the department and organisation.</p> <p>(DP 22): If developing an organisational change programme, consider incorporating a cyclical feedback system that encompasses all-level staff input, i.e. physicians, nurses, healthcare assistants, porters, clerks.</p> <p>(DP 23): Care delivery may be aided by clearly defined and consistently used language and terminology.</p>
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The GEDI WISE team were attempting to create a culture of change to deal with an emerging and unstable healthcare challenge (DP 13). Through case notes, interviews and observation it was apparent that communication was a lynch pin for positive or negative experiences within this culture of change for staff and, by default, patients. The literature refers to cyclical design systems which facilitate all staff input and involvement and give them a voice, enabling them to become change agents in their own right (Romme and Damen, 2007). Design principles 7, 20 and 22 emerged from various areas where this was observed within the Geriatric ED. Examples include the use of multidisciplinary ward round, the work of the CARE volunteers and the care of an older patient recorded as case notes A, in which a physician was able to manage and improve a situation based on access to information and communication with a family (Figure 38).

**Figure 38: Case notes A**

Admission of an 88 year old patient with advanced dementia, known to the hospice care and under the care of the visiting doctors. Developed respiratory distress; family panicked and called 911. Patient brought to the ED and placed in resuscitation. The family panicked and pushed for 'everything' to be done. The attending physician (AP) sat with them to explain the patient was dying. The family became hysterical and verbally abusive. Due to connections with the hospice/visiting docs programme, the AP was able to access notes containing the patient's wishes. Within 15 minutes, the AP was able to talk to the family, explain what was happening and the patient's wishes. The family relaxed allowing the patient to be made comfortable, be given appropriate medication to help respiration and admitted to palliative care ward. The patient woke up briefly later that evening, and family were able to say goodbye.

Observational feedback from staff and documented feedback from patients by the CARE volunteers reported that the CARE volunteer programme had reduced falls, and episodes of confusion and delirium. Significantly, patients reported reduction in anxiety and pain following interaction with the volunteers who are able to sit and talk with them, providing distraction therapies.

There were elements where staff experiences had been less positive, which is to be expected in any large scale change effort. However, observation of a quick and effective response by the GEDI WISE team to a concern raised by staff led to the development of DP4 (Figure 37). During a training session a number of night-shift staff expressed concerns about a lack of support and access to resources that were available to the day-shift staff. One member of the day staff, commenting on how beneficial the CARE volunteers were to his practice, received the response '*...yeah alright, don't make it worse; we don't have them!*' These data were fed back to the GEDI WISE team with the consent of the staff in question (see DP 6, Figure 37).

The team expressed concern for the staff and there was an immediate response to make the resources and support given to the day shift more available to the night shift. One change was to extend the hours of the CARE volunteers to midnight to give more support to night staff.

Given the scale of the GEDI WISE project, the effective speed and response of the leadership team suggests that this sort of problem may simply stem from an oversight in the communication process. This was observed several times: communication regarding the changes and their effectiveness in practice did not appear to be facilitated in a structured way (reflected in DP 9 and 21, Figure 37). This meant that if staff were not pro-active, their perspectives and concerns might not be heard or acted upon. Based on the suggestion of an integrated feedback system referenced earlier (Romme and Damen, 2007), this particular challenge led to the development of four design principles which consider various aspects of a communication feedback system (DPs 4, 6, 10, 19, Figure 37). Processes for patient and carer input into experiences of communication were less clear but did appear to make use of a hospital-wide survey sent out to all patients following an admission. A patient liaison service for patients and carers was also present in the department, which responded to concerns as they arose.

The need for communication about the changes in the ED extended across to other organisations and practitioners. This was an important element in the development of the new model of care. DP9 was drawn from case notes B and C (Figures 39 and 40) which present two situations where communication regarding roles was a key factor that facilitated or prevented the nurse practitioner from providing what she felt was the appropriate patient care.

#### **Figure 39: Case notes B**

A female patient (aged +65) was recognised by the nurse practitioner as a readmission to the ED. The medical history revealed degenerative hip problems and drug use. The patient was due for surgery but on several occasions had left hospital and refused treatment. The Nurse Practitioner referred patient to the Preventable Admission Care Team (PACT). The PACT team advocated for patient, contacting her son and the orthopaedic team, who were able to discuss issues with patient. She then agreed to surgery as her previous refusals were down to fear and the unknown.

#### **Figure 40: Case notes C**

An 80 year old woman with stage 4 ovarian cancer had recently completed a course of chemotherapy but been admitted to hospital with sepsis. On admission she was found to have a pulmonary embolism. The Assistant Physician requested palliative care input via the Nurse Practitioner, but recommended liaising with the oncologist first. The oncologist was defensive, claiming to be insulted at the request. The oncologist was rude to ED staff member making contact and appeared to be unable to differentiate between palliative and end-of-life care. The patient was discharged home to the care of the visiting nurses. The episode was viewed as a missed opportunity for palliative care support by ED staff.

The GEDI WISE retreat day is the final example of effective communication and collaboration, leading to on-going role development and best practice for geriatric care in the ED (DPs 14, 16, 23, Figure 37). Staff worked with their peers from other hospitals to discuss best practice and role development.

#### **5.6.7 Frame 6: Translation into application**

In this frame the design principles (Figure 37, Appendix 13) and broad design principles as they sat within Frame 5 (development of broad design principles) were rephrased and reformatted to make them accessible to older people, their carers and staff at St Thomas' ED in the UK. The objective of this frame was to develop heuristic statements that underpinned the broad design principles resulting directly from the analysis outlined in the former five frames. Essentially '*...making explicit what is in the heads of experts and practitioners so that it can be widely used by others in a range of local contexts to get improved outcomes...*' (Bevan et al., 2007, p.8).

The reworking of the presentation of the design principles and broad design principles was an important element as the language up to this stage was quite stiff and managerial, largely because the focus had been on understanding and appraising the development of the Geriatric ED. By Frame 6 the focus could move away from analysis and into a process of translating the recommendations to a UK audience. Language, presentation and style were important features to consider as the intended audience was a mix of clinical staff, managers, patients and carers. Therefore the final format needed to be easily understood and jargon free.

Frame 6 pulled again on the work of Plsek et al (2007) to inform this process. The approach was as follows:

- Frame the design principles within the applicable context
- State a specific goal for the context
- Offer the design principles as a series of recommended actions

By reconsidering the human experiences and observation points that informed the broad design principles and applying them to Plsek et al's (2007) process of 'context, goal, actions', the principles were able to be rephrased into a structured format with a clear process and tangible suggestions. This final format created a single document that could be provided to anyone with an interest in the topic (Appendix 12). Figure 41 contains an extract of this

document which captures the Broad Design Principle ‘communication’, and the way in which the use of specialist staff is recommended.

**Figure 41: Extract from the final presentation of design principles**

**Design principles**

*Context:* **If you are working in an emergency department and seeing increasing numbers of older (and palliative) patients...**

*Goal:* **and you want to improve the experiences of care delivery for older (and palliative) patients, their carers and staff by creating a new model of care...**

*Actions:* **then it might help if you focus on...**

**A: COMMUNICATION**

**Establish effective ways, firstly, of communicating with staff at all levels that helps them to understand their respective roles in providing high quality care to these patients and how they relate to each other, and secondly to disseminate information to the department and across the organisation.**

Do this through:

**3. Strategic use of specialist staff who:**

- a. Specialise in the care of older people (including older palliative care)*
- b. Can help to review processes and provide training to generalist practitioners*
- c. Can liaise with patients whose needs are beyond the remit of generalist ED staff*

On the completion of the analysis, the report to the funders (Blackwell, 2013) and the final document of design principles (Appendix 12) were fed back to the GEDI WISE team at Mount Sinai for comments, approval and validation of the work.

## **5.7 Application to St Thomas’ ED and dissemination in the UK**

Once the analysis was completed and validated the findings were fed back to the UK and the main study site St Thomas ED. This included:

- Providing a copy of the report and design principles to the research site to help inform development of the new ED rebuild project by providing new ideas and influencing the layout and use of space.
- Sharing the findings with ED staff in teaching sessions at St Thomas’ ED.
- Using the findings to inform the development of Stage 3 of the EBCD process as it sought to engage and invite patients and carers into the project.

Chapter Eight provides more detail of the influence of this fieldtrip on the study site as it was observed over the progress of the research project and ongoing dissemination to staff working at St Thomas' ED.

The exemplar used throughout the analysis highlighted the benefits of having specialist staff in the ED to improve care for older and palliative patients. At the conclusion of this research study (November 2014) the clinical lead and other managerial staff were discussing the use of volunteers, and had opened a frailty ward which was overseen by a geriatric doctor. These developments were acknowledged as being influenced by the design principles and feedback from this fieldtrip. Chapter Eight provides more detail.

One of the main challenges highlighted previously for this thesis was the lack of data regarding patient and carer experiences of palliative care in the ED. The fieldtrip served to demonstrate why this is complex data to capture and why the fieldtrip was unable to provide much in the way of content directly from patients and carers. The observations and case notes from the main and Geriatric ED did provide insight into the potential challenges they may face. The combination of this learning went towards informing the patient and carer recruitment strategy (see Chapter Six) and the planning for the co-design event (see Chapter Seven).

The final element to emerge from the fieldtrip related to the ongoing development of palliative care in the ED. Good working relationships were developed with members of the GEDI WISE team, in particular Dr Grudzen whose work had played a significant role in informing much of the thesis (Grudzen et al., 2010, Grudzen et al., 2011a, Grudzen et al., 2011b, Grudzen et al., 2012a). These continued after the fieldtrip and Chapter Eight discusses the developments in more detail.

Additional dissemination included a report focusing on the fieldtrip (Blackwell, 2014) and at two conferences; a poster presentation at the 2013 College of Emergency Medicine Annual Conference (see Appendix 15), and a presentation at the 2014 Florence Nightingale Foundation Annual Conference. The conference poster led to a request for a publication detailing the need for a new model of care in emergency medicine for older palliative patients, which was written collaboratively with Dr Grudzen (Blackwell and Grudzen, 2014). A number of other conferences, networks and teaching and presenting opportunities emerged as the thesis progressed which are discussed further in Chapter Eight.

## 5.8 Critical reflection

This period of extending the parameters of the study was exciting and added considerable value and insight to the conduct of the main study, as well as contributing to my personal development. The actual process of organising the fieldtrip was surprisingly simple and unproblematic. I had anticipated bureaucratic obstacles in gaining approval for the study and deliberately kept the aims and conduct of the fieldtrip simple. In addition Mount Sinai regularly hosts national and international visiting clinicians and has structures in place to support this form of knowledge exchange.

Once at the Geriatric ED I found the process of data collection an enjoyable experience. Data were recorded as outlined previously in the chapter, and Figure 38 showed that this included the use of audio field notes. While my written field notes were quite detailed, they were made in the clinical area during conversations and at times were quite rushed. As data collection was an iterative process, before I knew how to write my field notes I found it useful to privately record myself talking through and reflecting on the notes to consolidate what I had learned during that day. This process also helped to highlight where my notes were lacking, or if I needed to explore something further at the site the next day.

The process of data collection was enhanced by the staff that were welcoming, friendly and willing to be questioned about their practice and experience. At times I was asked to share experiences from the NHS and UK which often led to deeper conversations about care provision, providing valuable insight into the personal ethos and convictions of the staff. Their data reflected what I had witnessed in the UK, again demonstrating a resonance in experiences across EDs. One interesting factor was a lack of enthusiasm from several generalist staff toward the new department, who questioned if it was outside of their remit of work as ED clinicians. This seemed to depend on their involvement in the process and if they felt 'done to' or empowered, a factor I took note of in considering how to continue drawing staff into the EBCD process in the UK. It also mirrored debates in the literature about the role of staff in the delivery of palliative and less traditional forms of care provision in the ED (Smith et al., 2009, Grudzen et al., 2012b)

One aim of the fieldtrip that was not fully realised was the opportunity to talk with patients and carers about their experiences. Although some data were collected they were minimal in comparison to other data pertaining to staff experiences and organisational management. Given the paucity of published literature on the older palliative patient in the ED, I was

concerned that the study both in the UK and the US was increasingly one-sided and not reflecting a shared story. I considered this issue in relation to the data I had been able to collect from the few patients and carers who were willing to speak with me, alongside the case studies and observational data in the main ED compared to the Geriatric ED. Although it was lacking patient and carer, what had emerged was the type of factors that could impact on the experiences that UK patients might encounter. The GEDI WISE team had focused on the physical aspects of the experience, along with the use of additional staff to support and enhance the care of the generalist ED practitioners. I reflected that, given the parallels between the US and UK staff, there may be overlap between the US and UK patient/carer experiences. However, I tried to remain cautious and aware of these preconceptions so that I did not project them onto the patients and carers involved in the thesis, in case this assumption was false.

I found the process of data analysis and translating raw data into design principles quite demanding as it was a rigorous process. As stated previously, the process of analysis was adapted from the work of Plesk et al (2007) who had observed healthcare practitioners struggle to translate their actions into design principles. In this fieldtrip I acted as the design researcher, building design principles from the data shared by staff at Mount Sinai. As I come from a healthcare background I was more familiar with the terminology used by healthcare staff than of the design sciences, which is often simpler. I found it difficult to lift broad, generalizable principles and articulate them within a transferable framework, although I could recognise that they were there. This was a lengthy and arduous process but its undertaking broadened my understanding of the design element within EBCD first discussed in Chapter Three, as well as stretching my abilities as a clinical researcher and academic. Completing the process ultimately served to increase my recognition of the value in sharing learning by moulding unformulated statements about practice into translatable practical principles and recommendations.

Of particular value for the study but also my development was the opportunity to observe and spend time with researchers and clinicians whose work I have been learning from for several years, particularly Dr Grudzen and Professor Hwang. I used the opportunity to question them about their personal motives and inspiration for working in this field and conducting research that has informed this thesis (Hwang and Morrison, 2007, Grudzen et al., 2010, Grudzen et al., 2011a, Grudzen et al., 2011b, Meo, 2011, Quest et al., 2011, Stone et al., 2011, Grudzen et al., 2012a). Through such conversations our analogous research and clinical goals were

revealed and I was invited to collaborate on future publications and work where possible. Ultimately this has led to an invitation by Dr Grudzen to undertake a post-doctoral fellowship at New York University on completion of this thesis to continue researching in the field of ED-based palliative care. Such personal developments were not anticipated but were invaluable as the recently completed work with staff in the ED at GSTT in Chapter Four had left me feeling quite isolated in the EBCD process, despite the positive response of the staff. Meeting with clinicians who had recognised the same challenges in practice and were furthering the research and care in their own areas was inspiring. Their positive response and encouragement for my work increased my energy and motivation, and I returned to the main thesis with renewed belief in its potential to influence improvements in experiences of care.

## **5.9 Conclusion**

The exploratory fieldtrip into the new model of care being developed at Mount Sinai was a unique opportunity to expand the scope of the thesis. Throughout the chapter the narrative has demonstrated the correlations between US and UK staff and system challenges for providing palliative care in the ED. The implication of the fieldtrip is that the design principles created from the US work may be of use in developing solutions in the UK. Although patient and carer data was ultimately sparse, the positive reactions noted in observation to innovations such as the CARE volunteers and specialist staff suggests that UK patients and carers may also struggle with, and benefit from, services focusing on communication, transitions of care and a multidisciplinary approach within the ED. These speculations and the use of the work of the fieldtrip leads the narrative back to the UK and GSTT, where Chapter Six continues with the main study of the thesis and present EBCD Stage 3; the patient and carer story.



## **CHAPTER SIX: THE PATIENT AND CARER STORY**

### **6.1 Introduction**

In this chapter the narrative thread of the UK research project is resumed, picking up from Chapter Four which presented Stage 2 of the EBCD process. This chapter, enhanced by the learning and insight from the US research fieldtrip (Chapter Five) presents the conduct and findings of Stage 3: gathering patient and carer experiences.

### **6.2 Chapter overview**

The narrative is woven through the practicalities of preparing for data collection, the data collection process, analysis and validation with the patients and carers before resuming the first person critical analysis of this Stage.

### **6.3 Aim and objectives of Stage 3**

The aim of Stage 3 was to gather individual experiences of older palliative patients and their carers to collaboratively identify their shared story and determine their priorities for service changes in the ED. There were three objectives to achieve this aim:

1. Recruit and conduct 10-12 narrative-based filmed interviews with older palliative patients and their carers about their experiences of palliative care delivery while at St Thomas' Emergency Department.
2. Analyse the data and obtain participant validation for the identification of touch points.
3. Produce a DVD from the filmed interview data which presents the touch points as improvement priorities to be shown at the co-design event.

### **6.4 Practicalities**

To engage patients and carers and draw them into the narrative was a challenging proposition and to this end considerable planning went into Stage 3 of the EBCD process. Chapter Three introduced some of the ethical considerations for palliative care research. Within this section

the narrative explores these and other challenges, demonstrating the governance put in place to support and involve older palliative patients and their carers in this EBCD endeavour.

#### **6.4.1 Participant inclusion and exclusion criteria**

The recruitment process, discussed further below, relied upon staff to act as gatekeepers for accessing older palliative patients and their carers in the ED. In Chapter Four, Stage 2 demonstrated a well-documented challenge in palliative care research, that of variations in understanding and defining palliative care and the populations it encompasses (Addington-Hall, 2002, Goodman et al., 2012). Therefore the inclusion and exclusion criteria listed below, contains the clinical definition of palliative care first introduced in Chapter One (Beynon et al., 2011). Although inclusion was dependent on the ED attendance being caused by the palliative condition, the stage of the condition, for example last year or last month of life, is not part of the criteria. This was because staff had been predominantly concerned with patients who were actively dying in the department, not always recognising that for many palliative care patients, an ED visit is often associated with last year of life, reflecting a deterioration and decline in their condition (Rosenwax et al., 2011). Therefore the patient participant group reflected those causing most concern to ED staff, as well as palliative patients who may be less recognisable to ED staff.

As little is known about the experiences of patients who fit within the categories of unrecognised terminally ill patients and actively dying patients (Addington-Hall, 2002), the inclusion criteria was purposely kept open. The clinical definition of palliative care was also included to encourage staff to think about patients with conditions other than cancer (Sleeman and Murtagh, 2014). Regretfully, patients with dementia or conditions that could affect cognitive functioning were excluded from the study as appropriate screening, consenting and use of filming to capture their data posed ethical challenges that were beyond the capacity of this study (Addington-Hall, 2002, Goodman et al., 2012). However, carers for people with dementia were included as it was the personal experience that was being explored.

A geographical catchment area was part of the inclusion criteria as the study was conducted under the 'lone researcher' status and so capacity and time were limited. Patient and carer participants also needed to speak English. Palliative care for ethnic minorities is an under researched area (Goodman et al., 2012) and so, this is another group who would ideally have been included, but the study lacked the resources to provide for translators for the interviews

and film editing. As this chapter discusses, one patient and carer were recruited who were not as fluent in English as originally believed when the interview was arranged. Although they were able to provide valuable input into the study the language barrier was a challenge and meant that there was regrettably less interview footage that could be used in the final film.

The full inclusion and exclusion criteria were as follows:

*Patient inclusion criteria*

- Age 65+
- English speaking
- Patient at St Thomas' Hospital Emergency Department
- Living in Lambeth or Southwark
- Patients with long term/terminal conditions (adapted from Beynon et al 2011)
  - Palliative condition definition: Cancer, chronic obstructive pulmonary disease (COPD), heart failure, renal failure, liver failure, neurological disease (multiple sclerosis, Parkinson's, motor neuron disease) AND symptoms (pain, breathlessness, nausea, weight loss, anxiety) and/or complex social needs.

*Patient exclusion criteria*

- Non-English speaking
- A patient aged 64 or younger
- A cognitive impairment that prevented informed consent, e.g. dementia
- Expected to be in the final two months of life as per the AMBER care pathway guidance (Guy's and St Thomas' NHS Foundation Trust, 2015)

*Carer inclusion criteria*

- English speaking
- Living in Lambeth or Southwark
- Carer of a palliative patient aged 65+ who had used St Thomas' Hospital Emergency Department

*Carer exclusion criteria*

- Non-English speaking

#### **6.4.2 Patient-carer sample size**

The study protocol stated that sixteen interviews were to be conducted to reflect the staff sample size. During the recruitment and in consultation with the study supervisors this was reduced to ten as this was when data saturation occurred. Recruiting the required numbers in palliative care research is a widely documented difficulty (Addington-Hall, 2002), but one that is also experienced by action researchers working with any public user group (Coulter, 2011). The decision to reduce the recruitment number was supported by reflecting on these challenges and consulting with other EBCD researchers.

#### **6.4.3 Ethical considerations**

An ethics application was submitted to the National Research Ethics Service (NRES) via the Integrated Research Application System (IRAS). Approval was granted by the NRES Committee London-Riverside (reference: 14/LO/0136). Local Research and Development (R&D) approval was provided by the R&D department at Guy's and St Thomas' NHS Foundation Trust (reference: RJ114/N076). The application provided details of the management, governance and conduct of the study, along with approved versions of research material such as the information and consent forms (Appendix 16 and 17).

Building on the features catering for older adults at the geriatric-only ED at Mount Sinai, these and all other documents were printed using size 14 Arial font to improve clarity of reading. All information was broken into short segments with the purpose of each clearly stated segment.

#### ***Confidentiality and anonymity***

The information sheet (Appendix 16) clearly stated that the nature of the methodology meant that if participants agreed to take part in filmed interviews it was not possible to maintain their anonymity. However, identifiable data, such as full name and condition, were kept confidential and only segments of interviews were used for the DVD. All interviews were audio recorded and coded. This was to maintain participant confidentiality when the audio recordings were transcribed. Participants were assured that use of data in co-design events or publications would have any identifiable information other than their first name and condition would be removed. The participants agreed to have their real first name given on the DVD. Assurance was given that the filmed footage was to be used in the edited film only with the written consent from the individual participants. A data release form (Appendix 18) was provided to participants later in the study giving them the right to withdraw their data before the final film was made. This was to ensure that the fourth principle of process consent: 'on-

going consent monitoring' was adhered to. This is discussed further in the context of data analysis below.

### ***Risk***

Although there was no direct physical risk to any of the participants, the topic is sensitive and there were concerns that it could cause distress, particularly in the case of bereaved carers (Addington-Hall, 2002, Goodman et al., 2012). Fully informing participants of the purpose of the interview and its nature was vital, and was expressed throughout the recruitment process discussed in the following section. In addition, care was taken to encourage participants to ask questions and so begin to take ownership of the process. While preparing the information for participants the issue of managing potential discomfort or embarrassment at being filmed was considered. Advice for minimising discomfort was sought from patients and carers who had undergone filmed interviews about their experiences by the Community Involvement Manager for the National Council for Palliative Care. They provided personal experience of undertaking these interviews and of user involvement (Black, 2008). Additional advice and training into preparing, consenting and conducting filmed interviews with palliative care patients was provided by other experienced EBCD researchers (Tsianakas et al., 2012).

### ***Withdrawing from the study – participants and their data***

A final point of particular importance to those who are approaching the end of their lives and their carers was that of withdrawing from the study. The imminence of death can influence decisions to participate for patients and carers, and can lead to paternalistic responses from the staff acting as gatekeepers. This research was well supported by the ED but it is not uncommon for staff to be reluctant to engage with palliative care patient recruitment to research, citing concerns over their limited time, fatigue, unpredictability of condition and quite what their involvement would mean (Black, 2008). Some families may also exert pressure on patients not to participate for similar reasons, as well wanting to keep the remaining time for those close to the patient (Addington-Hall, 2002, Black, 2008). The patients themselves may also have these concerns, although an altruistic attitude is frequently reported, in which people prefer to use parts of their remaining time to share their experience and expertise (Addington-Hall, 2002, Black, 2008, Goodman et al., 2012). These were all considerations for the process of consent and, even for those who wished to participate, the variability of the condition meant that the degree to which they could participate was not clear and could change (Black, 2008, Coulter, 2011). EBCD relies on the collaborative working between healthcare staff and patients but the process for withdrawing from research

must always be explicit. The policy for withdrawing was devised, whereby participants were assured from the initial contact through to the final stages of the project that they were able to withdraw from the study at any stage without providing a reason.

Given the potential for patient demise during the study, a protocol was developed ensuring that the surviving next-of-kin would be given the option to withdraw or maintain the patient's data within the study. During the data analysis stage one of the patient participants died and the protocol was followed; this is discussed in more detail later in the chapter.

Withdrawal of interview data could be requested at any time up to the making of the final DVD. However, following the principle of on-going consent monitoring presented below, consent for use of the data was reaffirmed verbally and in writing to this point with clear information as to how the data would be used. Raw data, participants were assured, would be archived for four years at King's College London in a secure facility. All contact details would be destroyed unless participants chose to continue to collaborate in the study, and audio recordings deleted once analysis was complete. Participants were informed that the results of the data were to be shared with healthcare staff as part of service improvement work at St Thomas' ED and the study written up as this doctoral thesis, with publications to be submitted to professional journals and presented at healthcare conferences and used as the basis for international service improvement work.

## **6.5 Recruitment and consent**

The ethics application explained that the recruitment process had been devised as three steps:

Step 1: Identification and initial contact in the ED

Step 2: Telephone contact a week after the patient was discharged from hospital, or a week after their ED attendance, to provide more detail on the study and to arrange an interview date

Step 3: Signing of the consent form prior to conducting the interview

These steps were based on the five principles of process consent (Goodman et al., 2012). This is a method for refining normal ethical considerations to cater for more vulnerable people in research, particularly those who may have changing capacity in the degree to which they can participate (Dewing, 2008). The five principles are:

1. Background and preparation
2. Establishing a basis for capacity and other abilities
3. Initial consent
4. On-going consent and monitoring
5. Feedback and support

### **6.5.1 Recruitment step 1: Identification and initial contact in the ED**

For this part of the study principles one and two of consent ‘background and preparation’ and ‘establishing a basis for capacity and other abilities’ were applied before patients or carers were approached. This was done in consultation with the two main gatekeepers to the research site; the practice development nurse (PDN) and the clinical lead. The ethical considerations for these principles were to ensure that patients were not inappropriately approached or coerced into participating, and that they were provided with a manageable degree of information about the study (Addington-Hall, 2002, Goodman et al., 2012).

As step 1 of the recruitment was conducted in the ED while patients and carers were likely to be *in extremis* with their conditions, this step was simply to determine if patients and/or carers were willing to be contacted by phone following their discharge, to be told more about the research. The gatekeepers advised researcher presence in the ED for the early morning handover to make a short announcement to the staff about the study and the types of patients and carers who were to be recruited. A copy of the inclusion and exclusion criteria was given to staff, and posters were put in staff social area as reminders (Appendix 20). Then, as patients were admitted to the ED either via ambulance or the front entrance triage, staff were asked if they met the inclusion criteria and if it was appropriate to approach them. Although staff had relatively little background information or knowledge about the patient, they exercised clinical judgement about the frailty and capacity of the patients (Addington-Hall, 2002).

Initially the plan had been for staff to ask patients if they would be willing to be contacted following their discharge, and if they agreed a copy of the information sheet and consent form were provided. This was to avoid the research process becoming part of the ED experience and their narrative. However, during the recruitment process, face-to-face contact between the patient-carer and researcher proved to be a more fruitful method for encouraging participation, which was always conducted in consultation with the ED staff. A letter signed by the clinical lead was also provided, which stated that the research was supported by the

hospital and the ED, but that the normal care of the patient and carer would not be affected by their inclusion or refusal to participate (Appendix 19). This was to allay potential anxieties and to avoid patients or carers feeling they were being coerced into participating (Addington-Hall, 2002, Coulter, 2011).

A second method of recruitment using snowball sampling was also prepared, whereby existing participants or healthcare professionals from the ED who encountered suitable recruits would invite new participants into the study. This second approach was developed when considering the sensitivity of the research topic and the potential negative impact an ED visit could have for patients, which suggested that recruitment via the ED could prove challenging. Governance measures were also set in place to protect the privacy of potential participants until they were willing to be approached by the researcher. These included providing the patients, carers or staff who identified potential recruits with the study information and consent forms to pass on. One carer was recruited via this method.

In total, nine days were spent in the ED on this first step of patient and carer recruitment, during which time twenty four potential participants agreed to a phone call from the researcher after their discharge. The time the researcher spent in the ED was also used to re-establish relationships with staff following approximately six months away from the department (See Timeline: Figure 1 Prologue). Despite undertaking teaching in the ED on several occasions, a number of the early staff participants had left the department, and new staff were not always aware of the research. This is discussed further in the critical reflection. Throughout all of this stage of the EBCD process record logs were kept as part of the ongoing audit trail, detailing each element of the process: Log 1: ED recruitment; Log 2: Recruitment and process of gaining consent; Log 3: Patient and carer interviews. Other audit processes included four excel spreadsheets that recorded: all participant contact; a summary of the data collection; the development of the analysis; the validation process; preparation for the co-design event (Chapter Seven).

The first record log recorded the ED recruitment stage, documenting the number of patients or carers identified during each day, any issues while in the ED, an overview of the recruitment session, reflections on staff interactions and a self-critical reflection. Log 1 also contained the reflections and field notes from the observations made while in the ED. Figure 42 provides two extracts from this log (day three and day seven) to show the development of the recruitment process and observation, and some of the challenges in this undertaking.



**Figure 42: Extracts from Log 1: ED recruitment**

**Participants recruited:** 1

**Issues:** N/A

**Overview:** Recruited from 8am-1pm. Short day due to factors beyond my control. I was invited to talk to two potential participants today. This had been agreed with ethics but I have tried to avoid doing this so I do not become part of their experience. However it was suitable on both occasions. Only two suitable candidates today, one declined to participate, one agreed. I was able to spend more time with staff, building relationships and asking their experiences and understanding of palliative care. Staff are starting to recognise me and look out for patients.

**Contacts/staff interactions:**

- Palliative care link nurses. Both would like to shadow palliative care nurses and would appreciate input into the new processes replacing the LCP. One in particular is struggling in this role and hugely appreciative of any input.
- Spoke with a doctor who has a number of concerns and suggestions. Stated how useful it would be to have undergraduate training in palliative care, palliative pharmacology and more time to think about the concept and reality of dying. Discussion over starting to think about implementing or raising care plans for those in the last year of life, to avoid final admissions. Not often picked up until the patient is in crisis.

**Reflections**

**Building relationships and effective recruitment:** Today was an interesting day. My third day in the department recruiting and staff are starting to know me and remember my criteria and on each shift there have been at least three people who are actively looking out for me. I have been learning who to go to and where to look to identify potential patients which is making things smoother.

Staff have been very kind and interested and when I am able to explain the background they have responded positively and seen the need.

**Further evidence for Stage 2 findings, and challenges from this:** Each interaction with staff demonstrates an on-going lack of awareness of the services available, who to contact, or, if they do know who to contact they state issues of bleeps not being answered or not being able to have face to face contact. I am not yet sure how to take this forward and the palliative care team have all been silent and not replied to any of my e-mails stating I am back and recruiting. I will be teaching with them in September but it would be good to talk before then. There are always issues around staffing numbers and finances but I am certain there are simple ways to update.

Today I told several staff about the HOT clinic referral and the data in the palliative care folder. The palliative link nurses are very keen but are lacking in some knowledge around key issues and would benefit from more training. One is taking herself to the Marsden for two training courses later in the year. They are so keen and it is challenging that they are not yet supported fully.

**Tips for recruiting:** The carer recruited may prove challenging (see participant #C3 document). It is vital that I check all patients for discharge or death before making first contact to avoid causing distress or confusion.

**Personal impact:** Overall, although I am extremely tired, recruiting is going very well so far and I have been able to gather an excellent amount of data and a good number of people from the first few days.

**Participants recruited: 1**

**Issues:** The patient is very quiet and not very easy to understand. This could be due to current weakness and depression. Follow up and see if it is possible to film.

**Overview:** In the department from 8am-12:30 as I started follow up phone calls today, which can be quite time consuming. One potential participant located.

**Contacts/staff interactions:**

- Several conversations with staff members but these mostly around research in general, or conducting a PhD, than my actual research. However, I am building relationships and trust and also enjoying spending time with them.

**Reflections**

**Recruitment challenges and personal interaction observations:** Contact with participants. Many of this group are lonely and isolated, or afraid and struggling. Today I made contact with my first follow up phone call. This was very interesting and raised certain issues I will need to manage (see Recruitment Log 2)

**Numbers:** Today was a shorter day but still yielded one potential recruit.

**Non-participant observation:** I may need to spend more time observing rather than talking with staff. However, this is a challenge because all care goes on behind curtains, which is beyond my remit. I have observed a depth of compassion and care from staff in other interactions despite this, in things such as getting drinks or chairs for people, responding immediately to questions. That said, I can see where some carers or patients appear slightly frustrated by a lack of detail, and where this could be staff being so immersed in their own environment that they forget that their experience is not common knowledge.

Once it had been established that patients and carers were willing to engage in conversation at least, the third principle of the process consent, initial consent was applied. The principle of initial consent was an important one for this thesis as it ensured that all study information was accessible to the person to be recruited and sensitive to their needs (Addington-Hall, 2002, Goodman et al., 2012). This thesis has discussed the threat that certain palliative care terminology can hold for patients and carers, particularly the phrase ‘palliative care’ itself (Goodman et al., 2012). Patients may not understand the term, or know that their condition is classified as ‘palliative’. Hearing it from a researcher rather than their usual healthcare provider could easily cause fear and anxiety (Addington-Hall, 2002, Coulter, 2011). This lack of awareness was demonstrated in the staff data discussed in Chapter Four. Here clinicians outlined their concern when faced with dying patients who claimed they had not been told their condition could lead to death.

The screening of patient notes while they were in the ED provided some insight into the patient’s awareness of their prognosis. A definition of palliative care designed to be informative and non-threatening was provided at the very start of the information sheet, discussed previously (Appendix 16). The information sheet then outlined: the purpose and

rationale for the study and its dissemination, the reason that the patient or carer had been approached, directions for what participating would include, management of personal data, benefits from the study, right of withdrawal, and how to respond if there were concerns or complaints.

#### **6.5.2 Recruitment step 2: Telephone contact a week after the patient was discharged to provide more detail on the study and arrange an interview date.**

Not all of the twenty five patients and carers recruited in the ED had been given the information sheet. Some were well enough only for a brief conversation requesting permission for contact, or were recruited by staff who simply passed on their contact details.

The planned process in the second step of recruitment was a week after discharge:

- Telephone potential participants and reintroduce the study
- Post them a copy of the information sheet and consent form
- Follow up again a week later to see if they wished to take part

Ingrained in this and all subsequent steps and processes of the research was the fourth principle of on-going consent monitoring, which is explicit in continually checking that participants are both willing and able to remain in the study as it progressed (Dewing, 2008).

Hospital records were checked for the patient's discharge date to ensure that a week had passed before initiating recruitment, to give the person time to readjust from their hospital stay. This record checking was also to find out if the person had died, to avoid causing distress to carers with the phone call. Sadly some of the potential participants met in the ED died following their discharge back into the community. It was not possible to identify who had died once back in the community, and the follow up phone calls had to be conducted sensitively, although there could still be distressing interactions. Figure 44 below shares an extract from the second audit log: 'recruitment and process of consenting', where this occurred.

**Figure 43: Recruitment and process of consenting**

**Contact** 4 potential participants

**Follow up**

1 deceased

1 follow up phone call

2 no answer, continue to chase

**Issues**

- Interview cancelled last minute due to sickness. Need to rearrange.
- Death of potential participant
- Struggle to contact several participants

**Overview**

I was due to interview today but it was cancelled due to the condition of the participant's family member. Instead I made several follow up phone calls. One said to call back on Monday (15.9.14) and seemed interested, two I was unable to contact and one had very sadly died last week following their discharge from hospital.

**Reflection**

**Bereavement/participant's death:** I am researching a very unwell group of patients who are approaching the end of life. I have been trying to contact people who are in the last six months to last year of life. However, the lack of awareness of when people need palliative care, combined with when people need the ED means that many of the participants are incredibly unwell and in their final weeks of life. I am finding it challenging on a number of levels to call and learn that participants have died since I met them. Not least the potential distress I might cause to family members if I call and they need to let me know the person died.

**Flexibility:** This is probably the greatest lesson I am learning about this group. No date is ever definite, nothing is certain. I need to hold things very loosely and take advantage of whatever opportunities I am given. That said, for the most part, participants have been very kind and friendly and willing to help and take part.

Step 2 of the recruitment process presented various challenges such as those shown in the extract in Figure 43. Although twenty five patients were initially identified very quickly during the recruitment process, only ten people were actually able to participate. Table 14 presents a summary of the reasons for inclusion or exclusion in the study of the twenty five potential participants.

**Table 14: Characteristics of those included or excluded from the study**

Factor	Number
Interviewed	10
Not eligible	3
Deteriorated	3
Unable to make contact	3
Died	3
Declined	3

Ten participants were successfully recruited and interviewed. Detail provided below on the other fifteen listed in Table 14 reveals the complexity of this patient and carer group, and the challenge in conducting palliative care research. The reasons that fifteen potential participants were unable to participate are listed below as the challenges in recruiting palliative care patients and their carers has been eluded to but not fully explored. These reasons provide insight into the unpredictability of this vulnerable group and the flexibility required when conducting research with them:

- Not eligible:
  - one lived too far from the hospital
  - one was a carer who had not been in the ED with the patient
  - one had dementia which was not known when recruitment was undertaken
- Condition deterioration:
  - All three experienced condition deterioration which prevented their participation
- Died:
  - One person died in hospital before discharge
  - Two people died after their discharge
- Declined:
  - One person said they did not feel well enough to participate
  - One person had no recollection of being in the ED
  - One person declined on the day of the interview

With this final potential participant, it became evident once meeting the gentleman that an interview would be inappropriate and overly burdensome. He had very little to say about his

time in the ED, his health was deteriorating and he was in a low mood. Figure 44 contains an extract from the Log 3: patient and carer interviews which reflected upon this incident. Although a formal interview was not undertaken, the exchange provided valuable insight into future management of difficult situations and the role of the researcher as opposed to the role of the nurse (Bailey, 2007). This is reflected upon further in the critical reflection.

**Figure 44: Extract from Log 3: Patient and carer interviews**

**Semi-Interview: John\***

**Issues**

- Travelling to participant house with equipment and not knowing if I'm doing the interview.
- Participant very unwell
- Time constraints as participant waiting for hospital appointment and hospital transport.

**Overview**

I agreed to visit John at his home to discuss the potential for an interview, taking the filming equipment with me just in case. We had spoken over the phone and I had posted the information sheet but it had not arrived. We agreed to meet to try to reduce the input burden on John. I arrived at 9.30 and stayed until about 11.30. We did not carry out the interview. Although John has had numerous ED visits, these are the least of his concerns. We spoke about his time in the ED but there are significant other challenges going on in life and the ED visits were 'appropriate' each time (following collapses). Although some possible ED challenges emerged from our conversation we ultimately just chatted and he shared a lot about his life, thoughts, concerns and current challenges.

**Early Stage Analysis:**

- **Overcrowding in the ED:** John said the only thing he struggled with was how busy the department was. For his condition he is on 3/7 dialysis and is fatigued. The business of the department and often waiting a while for a bed was difficult. The new design of the ED may contain a different area that decreases the view of many other people, in addition a separate and capped bed area for older people means he won't be waiting as long should he require future visits.

**Reflection**

**Honoured to meet these people:** John ultimately didn't feel he had enough to share about his time in the ED, and I felt it was unethical to push this line of thought. He was still willing to talk with me and share much of his life. I am meeting people with a lifetime of learning and experiences. This is a generation I respect and care about and it is a privilege should any of them be willing to open up and talk with me. I must honour what they share and really hear what they are saying.

**Emotional burden/duty of care:** I was concerned that John might not be receiving good care in the community. I left with nursing concerns for his wellbeing having been in his home. However, these are beyond my role as a researcher, and in addition it is not my place to make judgements on his living condition without him raising concerns himself. I don't yet know what to do with this encounter but I will send him a 'thank you' card for sharing his time with me.

**Protecting myself:** I am reverting back to my clinical nursing perspective where I have boundaries up between myself and the participants but can still listen and care and hear what they are saying without becoming overwhelmed. As per the issue above, I am still affected, but I felt on leaving today, that I was stronger in myself than just a few weeks ago when I started this phase of data collection. I am still working to understand the new distinction of ‘researcher boundary’ which is very different from ‘nursing boundary’. But as I’m not sure if I can raise ethical concerns around care yet, I don’t really know what to do with what I see. An improvement in my coping mechanisms is that, whereas previously this would have drowned me in concern but not known if I could or should say something, now I know I can approach people and ask them for their input and for advice and follow that.

\*name has been changed

### **6.5.3 Recruitment step 3: Signing of the consent form prior to conducting the interview**

Ten participants were finally interviewed. Participants were given a choice of where they would like to have the interview and all selected their own homes. The lone researcher policy from King’s College London was drawn upon to reduce the risk in travelling to these locations, which is discussed in the critical reflection. Other than the case study presented above, the final stage of the recruitment process, gaining written consent, took place without incident, moving the narrative on to the process of data collection.

A final note in this section regards the fifth principle of process and consent: ‘feedback and support’. Here participants are kept informed of the progression, outcomes and end of the research process. Participants are acknowledged for their contribution and given the chance to feedback and reflect on the experience (Coulter, 2011, Goodman et al., 2012). Debriefing the patients and carers, and in some cases the on-going involvement in service change activities is detailed in more depth in Chapters Seven and Eight. In some research projects it may be appropriate to feedback an outline of the participant involvement to healthcare professionals involved with the care of the patient (Dewing, 2008). This did not apply to ED staff, but the GPs of patient participants were informed of their involvement in the research, with contact details for the researcher if the GP had questions about the study (Appendix 21). The GP letter served as a notification as part of the ethical requirements for conducting the study, as participants were to be referred to their GP if they had concerns beyond the remit of this study following their interview.

## **6.6 Data collection**

### **6.6.1 Preparing to interview**

Preparation for filming included a training course run by the Health Experiences Research Group at Oxford University, as well as informal training provided by an experienced EBCD researcher (Tsianakas et al., 2012). This researcher was also present for the first interview to provide support and feedback (discussed in more detail in the critical reflection). Following the methodology of EBCD, the interviews used a narrative approach and lasted approximately sixty minutes. On arrival at the participant's home time was taken to discuss the study in more depth, to give information about the processes of the interview and the remainder of the project, and to complete the consent forms. As per the ethics guidelines, before filming began participants were reassured that if they became distressed they would be asked if they would like to stop the recording, or they could request to stop at any stage. If they then did not wish to resume the interview, it would be terminated and the data destroyed. If they preferred, they were given the option to reschedule or to leave the project. The detail from the information sheet was repeated, that if any concerning issues arose during filming, or the participants became distressed, they would be advised to contact their GP, who would have been notified of their participation in the study once the date for the interview had been set.

When the consent form was signed the filming and audio recording equipment was prepared. As some people may have been reluctant to be filmed, participants were assured that they could undertake an audio recorded interview only if they so wished. A third option was given to potential participants that if they decided against being interviewed, they were still welcome to attend the co-design event. In practice eight people agreed to a filmed interview and two were audio recorded. The audio recording is discussed below, and its use in the DVD is presented later in the chapter. Once the filming equipment and technical factors such as sound and lighting had been prepared, the interviews began. Participants were asked a simple question relating to what took them to the ED on their last visit, and prompting questions were then given throughout the telling of their story. Appendix 22 provides a copy of the transcript from the first interview 'Ann's story'. As stated previously, all ten interviews were conducted at the individual participants' houses.

Table 15 provides an outline of the participant characteristics. The first names have been included with the permission of the participants. No pseudonyms have been used for



consented participants. The participants ranged in age from 62 (one of the carers) to 86, the median age was 75, and six were female. As Table 15 shows, the majority of the patient participants were affected by cancer, the other conditions were COPD and a degenerative neurological condition. Of the participants there were two married couples, Ron and Jean, Manubhai and Shakuntla, one who cared for the other. In both cases each chose to be present while the other was interviewed. It is necessary to acknowledge that this may have impacted on the freedom of disclosure in these interviews.

**Table 15: Participant characteristics**

Interview	Name	Age	Patient or Carer	Condition (detail if known)
1	Ann	65	Former carer for her husband, Alan. K	Alan had lung cancer
2	Ron	86	Carer for wife, Jean	Jean has several degenerative conditions
3	Jean	83	Patient	Degenerative neurological condition (not dementia)
4	Angela	66	Patient	Bowel cancer
5	Heather	76	Patient	Liver cancer
6	Alan. F	80	Patient	Prostate cancer
7	Fred	78	Patient	COPD
8	Manubhai	74	Patient	COPD
9	Shakuntla	64	Carer for Manubhai	Manubhai has COPD
10	Barbara	63	Former carer for her husband, Dave	Dave had metastatic liver cancer

### 6.6.2 Post-interview processes

On completion of the interview the audio recording was given a code and sent for external transcription, as with the staff interviews. The filmed recording was downloaded onto a secure network and the film cassette stored in a locked cabinet at King's College London. Field notes were made in a log similar to those already presented and provided an overview of the interview, reflecting on any issues and early considerations for the analysis. A folder was created for each participant on the secure server at King's College London containing details of all contact made, with dates and times. This provided a transparent audit trail of the involvement of the patients and carers. It also meant that if any concerns did emerge with the study, the conduct could be traced back, step by step. Once the transcripts were returned they were analysed using framework analysis; this is discussed in more detail in the next section. A card was sent to each participant following their interview, thanking them for their input and for sharing their story.

### 6.6.3 Managing the data collection process

Despite careful planning and preparation, conducting the interviews was not without its challenges. Working as a lone researcher and going to unknown locations meant that it was never clear how simple the interview would be to conduct, or what the quality would be. The extract given in Figure 44 is an example of when an interview was not appropriate for the patient, and a distressing experience to manage as the researcher, not a nurse. The critical reflection explores this aspect in more detail, but it is important to note that early on in the interview process, counselling was offered to debrief after each interview to help manage the changing role from nurse to researcher with the new boundaries this contained.

The initial set up was an important part of the interview process. Despite having received training in conducting filmed interviews, it was difficult to navigate the balance between sensitive listening and focus on the participant, and preventing technical errors that could affect the quality of the data. One such challenge was the microphone which attached by a clip to the clothing of the participant. It was extremely temperamental and would create feedback if disturbed by the slightest movement. Across all the interviews this was an awkward feature. Fixing the microphone meant stopping the filming, thereby interrupting the flow of the narrative. Figure 45 contains an extract from Log 3: patient and carer interviews reflecting on this issue following interview eight with Manubhai.

**Figure 45: Extract from Log 3: Patient and carer interviews**

Interview 8: Manubhai	
<b>Issues</b>	<ul style="list-style-type: none"><li>- Manubhai has quite a strong accent, English is his second language, and due to his COPD he finds it difficult to talk and breathe at times. This may affect the available footage.</li><li>- The interview was broken up by people coming to the house, phone calls and issues with the mic.</li><li>- Manubhai would often stop the interview to tell me what he wanted to say. He would then say something slightly different when I started filming again. He was also very concerned that he was saying what I wanted, even though I kept reassuring him that I wanted his story and his experience. The audio recorder was kept running for the whole interview however, so I was able to capture all of the data.</li></ul>
<b>Overview</b>	I arrived on time and was made welcome at Manubhai's home. I had some issues getting the microphone set up appropriately which has been an issue in all interviews as it is very temperamental.

Manubhai was identified by a staff member. The first contact with this gentleman happened over the phone via his wife Shakuntla (Interview 9). During the interview Manubhai was very careful to think about all he had to say in order to find the English to express himself. Although this was a long process it was the one that best suited his needs. He implied that his

wife played a role in his ED experiences and so Shakuntla was invited into the study and a date set to interview her. However, once the interview was underway it became clear that there had been a misunderstanding and she had often called for the ambulance to take Manubhai to hospital, but at his request had not accompanied him. The interview continued as this provided insight into the perspective of the carer who is away from the patient and the interview attempted to explore Shakuntla's experiences from the 'other side' of the ED as it were. Frame 6 outlines how these data were ultimately used in the research.

Across the interviews the participants shared a range of experiences, positive, negative and neutral. Positive experiences, although easier to discuss, were quite challenging to explore as people seemed to accept that something was good without always recognising why. A neutral experience indicated that the participant either had little memory of the ED, or the ED experience had not been a significant event for them. In the retelling of difficult or negative experiences two participants did become visibly distressed. In both interviews the participants who became upset while sharing their story were bereaved former carers. As per the study protocol the participants were asked if they wished to stop or end the interview, and both were contacted after the interviews to see if they required referring to their GP for further support. Figure 46 contains an extract from Log 3: patient and carer interviews, reflecting on one of these interactions in the interview with Ann, a former carer for her husband.

**Figure 46: Extract two from Log 3: Patient and carer interviews**

Interview 1: Ann
<p><b>Overview:</b> An experienced EBCD researcher and colleague kindly accompanied me to give support and help if I had issues with the recording equipment. Ann was informed prior to this and agreed. We arrived at Ann's house at 13:30 and stayed until 15:00. The interview went incredibly well. We had to stop a couple of times as Ann was crying, and again a couple of times as the microphone was being disrupted. This probably couldn't have gone smoother. Ann gave feedback there were points where I was silent and she wasn't sure she should speak and would have valued more input. This was actually because I digesting what she had just said and was completely overwhelmed with this new aspect of data. I have a lot to learn from this first interview in terms of communicating information prior and after the interview (see reflection) however, it actually went remarkably well – I'm not sure it could have gone better.</p>
<p><b>Reflection:</b></p> <p><b>My communication during the interview:</b> The point in the overview regarding my silence at times during the interview; hearing from a wife of a dying patient was an incredibly humbling and emotional experience. It is also very draining and I am exhausted and finding it hard to even write at the moment. Hearing from someone what they needed, what would have helped, what wasn't right – it is heart wrenching and inspiring at the same time. At this point I am totally overwhelmed and unable to even start processing properly, although some things really leapt out.</p>

It was the tenth final interview that proved most challenging in the management of participant distress. Barbara was first recruited in the resuscitation room of the ED following the admission of her husband Dave. She was distressed and unhappy in the department and opened a conversation that led to her being invited by the researcher into the study. A date was set to conduct the interview but Dave died shortly before this. Barbara was asked if she wanted to leave the study but she stated she wanted to share her story. The interview was conducted a week after Dave's funeral against all expectations that she would understandably withdraw from the project. The support network of thesis supervisors and a counsellor from King's College London were aware of this situation and it was felt that the interview could serve as a cathartic process for Barbara. This proved to be the case but in discussion with Barbara it was evident how deeply the ED experiences had impacted upon her. Indeed both of these interviews with Ann and Barbara proved to be powerful examples of the impact of the ED interactions and the lingering memory that relatively short healthcare interactions can have on the carers of palliative care patients, with feelings from both women being expressed just as strongly.

The process of data collection also provided some opportunities to enhance the study. The study had been designed with the aim of low participation burden and minimal effort from palliative care patients that would still provide useful data (Goodman et al., 2012). Going to the homes of the participants appeared to serve this purpose. Most seemed pleasantly surprised when they found out they would not have to travel for the interview and this appeared to be an important factor in the early stages of recruitment. Being in their own homes meant that people were comfortable and on their own territory, rather than in a medical institution where they were part of someone else's system.

One such example came from the second and third interviews which were conducted simultaneously with Ron who was the carer for Jean, although analysed as separate interviews based on their different perspectives and stories. Ron was identified through the ED by a staff member. During the second stage of recruitment the phone calls were always with this gentleman who spoke on behalf of himself and his wife, Jean. Ron was willing to participate but Jean declined. Ron had a background in television and said that based on this he was happy to be audio recorded but did not want to be filmed. On the day of the interview both Ron and Jean were present. As the interview progressed Jean began to add in comments, correcting Ron on certain points before openly sharing her own thoughts and feelings of her ED and health experiences. At the conclusion of the interview she willingly signed the

consent form to allow the inclusion of her story. Had she refused, her data would have been destroyed and only Ron's included.

The informal observation was conducted during the first stage of recruitment (see Figure 42). Observations focused on the use of the environment, its impact on interactions between staff and patients and carers, the different resources and pathways used to care for older people with palliative care needs, and to gain an understanding of the department and how it functions. These data were used to aid the analysis of patient and carer interviews, as well as providing additional data to support the co-design event when considering service improvements (Chapter Seven). In practice the non-participant observation was initially not particularly insightful due to previous personal experience of working in the department as a nurse, which hindered objective viewing of the running of the ED. It was not until analysis of the patient and carer stories took place that the observations were understood in terms of their impact on the patient and carer experience. Figure 47 below contains an example to highlight this point.

**Figure 47: Observed patient-staff interactions from the ED**

**Case example:** A lady recruited as a potential participant who died shortly after her discharge from hospital. During her time in the ED I witnessed several practitioners going to her cubicle on a number of occasions. When I spoke to her about the study she was tired and irritated. She said she wanted to put some cream on her chest which was dry and then eat her sandwich as she hadn't been able to eat for several hours. Whenever she tried, she said, another person would come into see her, move her belongings and then leave, pulling the curtain back away from her. She wanted the curtain left so she could have some peace and privacy to use the cream. I left and drew the curtain as she asked. I ended up doing this on three more occasions as I then noted the ED staff doing exactly what she had described.

Discussion of data analysis below explores the meaning of this sort of ED-based observation in more depth in the context of the data from the patients and carers. The critical reflection offers more depth into why this was not immediately seen as impactful on the experience of the patient, or the effect it could have.

## **6.7 Data analysis**

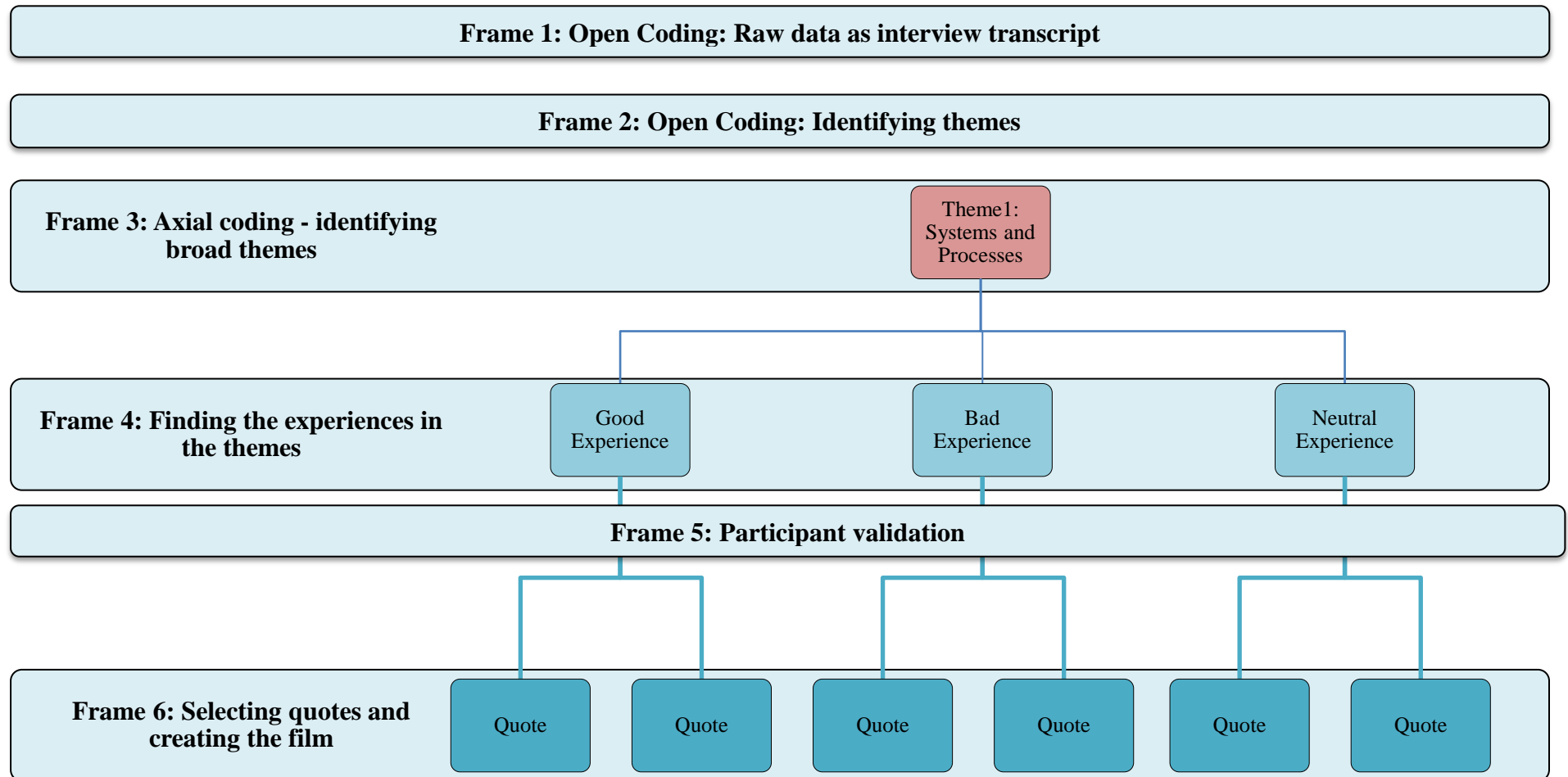
The process of data collection provided a means for patients and carers to share their experiences of being at St Thomas' ED in their own words. The purpose of the data analysis, as with the staff data, was to explore the individual narratives to identify the touch points, the

definitive moments that make or break an experience. These were translated into a shared story from which patients and carers selected improvement priorities. As with the process of analysis in the two previous chapters, this section uses six frames to demonstrate the progression of the analysis from its raw transcript/footage format into a series of coherent themes and improvement priorities that are shown on the accompanying DVD (Figure 48).

The staff data were collected as semi-structured interviews which provided a framework for the analysis. Framing was a more complex issue with the patient and carer data which comprised ten separate narratives. Two early stages of grounded theory, open and axial coding, were used to provide a format for deconstructing the data within a recognised theoretical framing approach for systematic data analysis (Green and Thorogood, 2009). Once these principles of coding had identified shared themes across the narrative in Frame 1 to 3, Frame 4 tied the narratives together to locate the shared experiences. Frame 5 presented this work to the participants for their validation, input and selection of the most important themes for improvement in the ED. Finally Frame 6 used the data to create a DVD which presented the priorities for improvement as a shared narrative, drawing on the filmed footage from the interviews as agreed with the participants. Figure 48 provides a visual representation of the six frames of analysis which are presented below.

The culminating section of the data analysis contains a discussion of the final themes selected by the patient and carer participants. The discussion draws parallels between these findings, the staff data analysis and the findings from data collected at Mount Sinai, pulling these three independent but related chapters into the cohesive shared story of the co-design event (Chapter Seven).

Figure 48: Visual representation of thematic framework analysis



### **6.7.1 Frame 1: Open Coding - data collection and identifying first level categories**

In Frame 1 the data were collected and analysed using the first stage of open coding. In grounded theory this is when raw data are scrutinised at a line by line level to start exploring what is going on (Green and Thorogood, 2009). For this thesis, this meant that the interactions and processes leading to the ED admission or occurring during the ED visit, and subsequent journey back home were scrutinised to identify touch points. Field notes made during the interviews, (the logs cited previously) provided an overview of the type of experience portrayed in the narrative, for example if it had been positive or negative. Once transcribed, hard copies of transcripts were printed and words, phrases and statements were highlighted with notes identifying possible themes. This information was compiled from the interactions and processes conveyed across all ten interviews into first level categories, for example being asked the same questions by different staff members, or feeling positive that the ED will help resolve the medical emergency (Table 16).

### **6.7.2 Frame 2: Open Coding - identifying second level categories**

In Frame 2 the second stage of open coding was conducted in which second level categories that begin to find patterns in the data were identified, for example issues relating to communication or expectation of the ED (Table 16). Transcripts were re-read, analysing the notes, words, phrases and statements that had been highlighted as first level categories for connections, relationships and similarities across the ten narratives. In order to maintain the individual narratives while searching for these relationships, each participant's transcript was coded by colour. Next the connections, relationships and similarities were grouped together by subheadings into second level categories. Figures 49 and 50 provide a visual record of this process which is summarised in Table 16. In total 33 second level categories were identified across the narratives. Table 16 contains an extract from the analysis document which shows how the data in first level categories were grouped into second level categories.



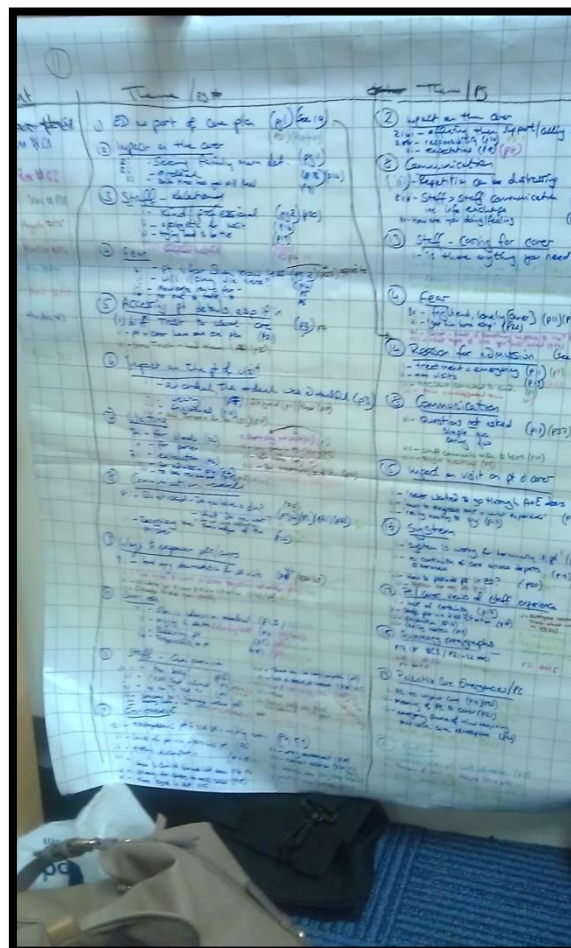
**Table 16: Extract from open coding document showing how first and second level categories were synthesised**

Participant and Page Number	First Level Category: positive (+ve), negative (-ve), neutral (=)	Second Level Category
<p>Ann pg. 4,9,12,21,22/ Angela pg. 16/ Barbara pg. 4,17,19,/Heather pg. 20/ Jean pg. 37 Ann pg. 10/ Barbara pg. 4</p> <p>Ann pg. 10,2p Ann pg. 10/Alan pg. 5/ Angela pg. 22 Jean pg. 19 Angela pg. 9 Angela pg. 12 Angela pg. 7,26/Heather pg. 1,2/Shakontla pg. 14/ Barbara pg. 2 Angela pg. 27/Heather pg. 22 Barbara pg. 4</p>	<p>Simple or caring questions not asked (do you have a plan/what do you want/can we call someone/how are you doing/feeling) (-ve)</p> <p>Recognising/not recognising the knowledge of the patient/carer (+ve/-ve)</p> <p>Repetition can be distressing (-ve)</p> <p>Staff to staff communicating information (+ve/-ve)</p> <p>Staff comments taken to heart (+ve/-ve)</p> <p>Asking the right questions (+ve)</p> <p>Giving unhelpful information (-ve)</p> <p>Experiences of staff to patient information sharing (-ve/+ve)</p> <p>Communicating unknowns (-ve/+ve)</p> <p>Experience of staff talking to carers (-ve/+ve)</p>	<p>Communication</p>
<p>Ron pg. 3 Ann pg. 13/Barbara pg. 23 Angela pg. 5/Fred pg. 5/Manubhai pg. 9 Angela pg. 14 Angela pg. 14 Heather pg. 12,21 Fred pg. 14 Barbara pg. 3 Barbara pg. 11,12 Barbara pg. 23/Alan pg. 4-5</p>	<p>To be repaired, mended (+ve/=)</p> <p>Will be negative (-ve)</p> <p>Not worried, want to be fixed (+ve)</p> <p>Go with the flow (+ve/=)</p> <p>Expect a long wait/stay (=/-ve/+ve)</p> <p>Don't want to go back (-ve)</p> <p>An annoyance (-ve/=)</p> <p>That staff would care (+ve)</p> <p>Have to fight for care (-ve)</p> <p>ED experiences influences feelings about the rest of the journey (=/+ve/-ve)</p>	<p>Expectations of the ED</p>

**Figure 49: Open Coding - identifying second level categories**



**Figure 50: Open Coding Stage 2 - identifying second level categories**

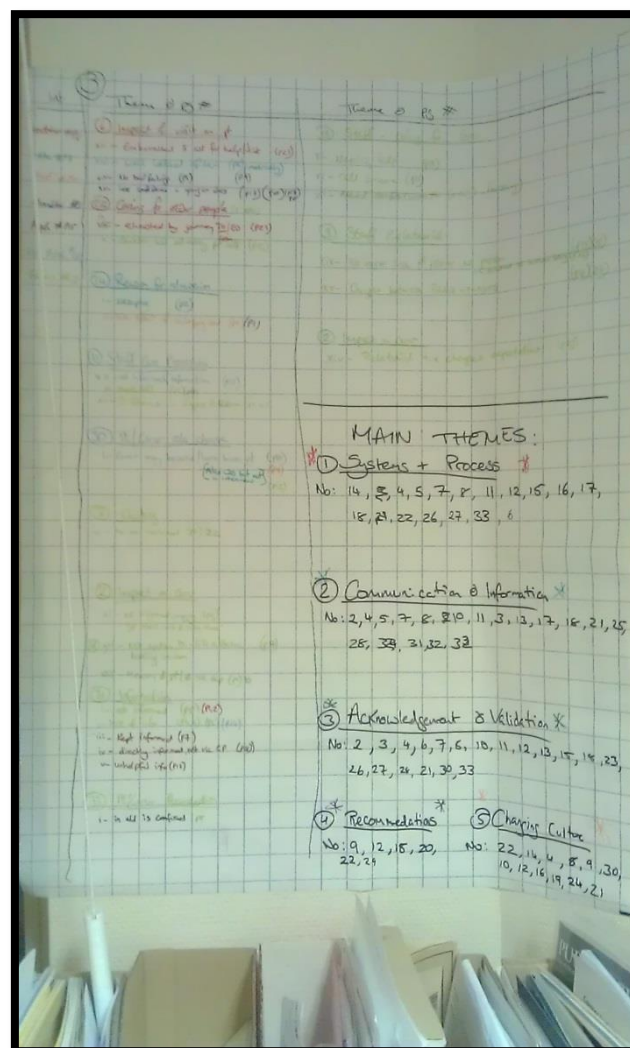


### 6.7.3 Frame 3: Axial coding - identifying themes

Frame 3 employed the use of axial coding. This is an important step in grounded theory whereby second level categories are analysed for wider themes. Specifically data are appraised for relationships across the ‘*when, where, why, how and with what consequences an event occurs*’ (Holloway and Todres, 2007, p.199). The five themes that emerged during this process of axial coding were: Systems and Process; Communication and Information; Acknowledgement and Validation; Recommendations; Changing Culture.

While this analysis was in progress, the transcripts were sent to the film editor who helped create the DVD and provided secondary analysis of the data. In both analyses the same five themes emerged populated with similar distribution of the second level categories. Figure 51 provides a visual record of how this process was initially recorded.

**Figure 51: Visual record of Frame 3 - axial coding**



#### **6.7.4 Frame 4: Finding the shared experiences in the themes**

In Frame 4 the underlying experiences in the themes and second level categories were re-examined to draw out the quotes that best exemplified the shared touch points across the narratives. This was an important stage as it brought the five rather starkly named themes to life in the context of experiences of the patients and carers in the ED. Drawing on the categorisation of the data in the first two frames, the ED experiences of the participants were identified as being positive, negative or neutral which helped with the recognition of touch points. Colour coded tables were developed for each theme containing a description of what the theme represented, and quotes which contained touch point moments. The themes were colour coded as follows:

- 1. Systems and Process**
- 2. Communication and Information**
- 3. Acknowledgement and Validation**
- 4. Recommendations**
- 5. Changing Culture**

Table 17 below, contains an extract from the theme ‘Communication and Information’. This is given as an example here as issues around communication and information had also been identified in the two preceding chapters by ED staff at St Thomas’ ED, and within the findings from the fieldtrip to Mount Sinai Hospital. It is therefore, a consistent theme throughout the thesis.

**Table 17: Theme 2 - Communication and Information**

Participant	Pg. and Time	Quote	Comments. Positive, Negative, Neutral
Ron	P2 Approx 3 min	It was very good indeed and in fact we had no province of complaint whatsoever. It was very pleasing. The staff were very good. What I like about them, they announced who they were, which is a nice touch. They were very friendly and their attitude was very friendly. They weren't just saying, well here I am, get on with it, sort of thing, they were all very, very friendly um and it was, I rather enjoyed it.	Positive – communication was excellent
Jean	P37 01:05:35	Because that, in communicating in that way, you are giving the person the knowledge that you understand how they feel and that is very important because if you're left on the side and you hear the nurses and doctors talking about you, you feel, oh golly I could have told you that. (Int – Yeah, yeah) It's, it's a much better approach to go face to face and ask the question of the patient. You'll soon know if they can't answer you and if they can't tell you. But if you ask it of them, that's much better, it's from the horse's mouth.	Also Acknowledgement and Validation  Positive/neutral – staff need to communicate with patients about their care, not talk about them but not to them.
Heather	P15 00:25:23	There was no kind of um reassurance coming off of them. It was just like, just another person... whereas like when I was in the second time,... she was really, really nice, really nice that somebody I know was looking after me and I think I got upset, upset and she was looking after me again and there was nothing like that the first time. I was just another person. I mean I know we, we all need help and that but I, I was completely lost cos I didn't have no-one with me and, you know, I had to go on my own because he couldn't, he couldn't do it because this one.	Also Recommendations Acknowledgement and Validation Negative/positive – the different experiences were down to how the nurse related to Heather and made her feel she wasn't alone or unseen.

#### **6.7.5 Frame 5: Participant validation and selection of improvement priorities**

In Frame 5 the analysis and identification of themes were submitted to the patient and carer participants for their validation, and for their selection of the main themes which would be represented in the DVD (Frame 6). From this point on the themes were classified as improvement priorities to begin moving the data towards the co-design event and the practical considerations of influencing practice in the ED. Frame 5 also shows how the usual EBCD processes employed to carry out this work were adapted to cater for the needs and vulnerabilities of the participants.

### *Adapting the validation process*

As stated briefly in Chapter Three, in a typical EBCD project the individual films would be returned to each participant for them to review the footage and provide consent for its use. Once consent is given, the interview footage is compiled into a short film and presented to all of the patients and carers for their review and appraisal. They then work collaboratively to provide feedback and select improvement priorities to take into the co-design event using emotional experiences mapping exercises (Donetto et al., 2014). The designed plan for this stage was to send participants a ‘data validation package’ containing:

1. A copy of the individual film to be sent back to each patient and carer with ‘data release form’ (Appendix 18) allowing their data to be used in the edited DVD (approximately 25-30 minutes in length in total) and for future service improvement work.
2. A short survey presenting the themes with space for participants to provide validation of the improvement priorities, and if they best represented the issues that were most significant in their ED experience.
3. Space to rank the three most important improvement priorities based on their personal experiences on the survey provided, as with the staff selection process.

This plan was adapted based on two factors. The first was the severity of the patient participants’ conditions, and the second was the limited time frame and resources of the overall project. Based on these two factors the co-design event was planned to take place three weeks after the final interview was conducted. It was not feasible to post copies of films back and await a response, plan and undertake a validation event and then make the DVD within that time scale. Therefore a new plan was formulated to gain the approvals and consent required for the co-design event:

1. With the agreement of each participant a second visit occurred.
2. The DVD was provided and the transcripts were reviewed in person
3. Face-to-face consent was gained including signing of the footage release forms.
4. In conversation about the themes and interviews the improvement priorities were drawn out.

Ron and Jean were given just their transcript as they had not been filmed and declined an audio copy of their interview. A laptop was taken to other participants’ houses in case they did not have a DVD player.

To make the process of validation clearer, quotes were highlighted by colour according to the theme they appeared to represent, as per Frame 4. Where quotes could refer to more than one improvement priority they were underlined in the other colours. Figure 52 contains an extract from Ann's Story as an example. Appendix 22 contains the entire coded transcript.

**Figure 52: Coded extract from Interview 1: Ann's Story**

I would get Alan's toilet bag ready and brace myself literally to tell him we've got to go Alan, we've got to go over to A&E and he would go oh no, not because of the staff, not even because what they were going to do with him because they were going to help him to, to make sure he got his next chemotherapy, but it was the ordeal and the ordeal was dreadful and I think as you, as we got more into the uh treatment and the reality of what was really happening my fear was that something would happen to him in the A&E and he would die there uh or he'd die on the way or into the ward and I think I was wanting to say look I know what it is, could you just please take him somewhere where this can happen and not here, and it's of course you wait for, **you wait for the bloods to come back, you wait for the porter, you wait for, and it could be done differently**

Colour code key

\* **systems and processes**

\* **acknowledgement and validation**

\* **communication and information**

### ***Gaining validation***

As with the staff data the improvement priorities were classified in terms of what the issue seemed to be, why it appeared to have occurred, and why it was important. This was discussed as it related to each individual's experience, but other interviews were drawn upon to demonstrate similar experiences. Using the colour coding, the participants considered each extract against the improvement priority it represented. Participants were asked for their opinion on seven points:

- 1) Did they feel the analysis was an accurate representation and understanding of their experience?
- 2) Did they agree with the overarching improvement priorities?
- 3) Did they agree with the extracts drawn out to represent that improvement priority?
- 4) Did they feel anything had been left out?
- 5) Did they want anything *not* coded to be included?
- 6) Did they want anything currently coded to be removed or deleted?
- 7) Were they willing to release the data to be used as per the study protocol?



The only major thematic change at this stage was the renaming of improvement priority five, originally called ‘Changing Culture’. It had been so named because it incorporated a number of factors that related to the personal culture, for example changes in their own health and life style, or experiencing care within a changing healthcare system. However, during the validation process some of the participants assumed this title referred to racial demographic changes in the UK and was implying that changes or problems in the NHS were the result of immigration policies. This occurred despite a description of the improvement priority being given verbally and in writing, and where extracts from the interviews were shown relating their specific experience. When participants gave this response it led to a discussion about the improvement priority in greater detail. When the misunderstanding had been dealt with there was agreement with what the improvement priority actually represented. However, as the word ‘culture’ acted as an unintentional trigger point for some people, to avoid further confusion the improvement priority was renamed ‘Changing Expectations’ to refer more clearly to the changing expectations that the patients and carers had about their own abilities and towards the ED based on their experiences. This made it more explicit and removed the inferred racial implications.

During this interaction all ten participants agreed to sign the release form regarding rights to the data collected and its future use which included teaching, presentations and publications. Some minor quotes were withdrawn at the participant’s request, but all agreed to the use of their data in the ways outlined previously.

### ***Selection of improvement priorities***

Next in Frame 5 was the selection of improvement priorities that the patients and carers felt were most important based on their experiences. Similarly to the selection of improvement priorities by staff, a short document containing a ranking survey was provided (Appendix 23). The results were recorded and calculated by popularity to identify the three deemed most important:

1. Communication and information
2. Systems and processes
3. Changing cultures (latterly ‘Changing Expectations’)

Table 18 presents this record with the selected priorities highlighted in red. Table 18 also contains the explanation for the selection of improvement priorities given by participants.



**Table 18: Selection of improvement priorities according to theme by patients and carers**

Theme	Improvement areas	Rank 1	Rank 2	Rank 3	Explanation of selection.	Explanation of selection (cont.)
1	<b>Systems and Process.</b> To do with the overall health system and A&E specifically e.g. waiting times, environment	6	1		Ann found it too hard to choose between T2,3 and 4. She eventually ranked T1 as '1' and T5 as '2'.	Fred appeared to imply that T2 was most significant to his good/neutral experience, but he felt strongly about T5 although certain factors do not directly correlate to my topic focus. T1 was also significant to him.
2	<b>Communication and Information.</b> The encounters you had with staff, how information was shared between services, staff and with you.	7	1		Ron and Jean also struggled to choose. In the end they placed themes 1,2,3,5 as equal and T4 as '2'.	Shakuntla answered for herself and Manuhbai who is currently in hospital. Given the aspects that she spoke about most today, T1 and 2 are the key issues, with T5 being the next significant point to come out from their data.
3	<b>Acknowledgement and Validation.</b> How well your own experience was understood and recognised by staff. If you were supported or unsupported. Roles and impact on patients/carers.	2	1		Heather died during the research process. Her husband Ken chose to keep her data in the research. On her behalf and in light of her interview data he selected T5 and T2.	
4	<b>Recommendations.</b> Suggestions put forward for improving the delivery of palliative care in A&E.	2	1	1	Angela felt that T1 and T2 were of equal importance. T3 and T5 followed, and T4 was last. T4 was graded in this way as she recently found that her cancer was gone and didn't want to comment on palliative issues.	
5	<b>Changing Culture.</b> Factors relating to an ageing population with different care needs who now need to use the A&E. Other cultural changes.	2	4		Alan gave his ranking as the data pertained to his wider experience of the health system, rather than ED-specific, but there are important overlaps and interactions.	

### ***Challenges in process: selecting improvement priorities***

Participants found it difficult to select and rank the priorities for various reasons. Either the improvement priorities were considered to be of equal value, or for different reasons the participant struggled to make the decision. As with all stages of the thesis an audit trail was kept of all interactions with participants. Frame 5 used a Validation Log to record these individual feedback sessions, extracts of which are shown in Figure 53, providing further information on the selection process.

**Figure 53: Extracts from data validation log**

#### **Feedback to Alan (Interview 6)**

I had a very pleasant visit with Alan for about an hour and a half. We went through his data and he gave me permission to use it as per the protocol. As with all previous validation meetings, he repeated much of what he had said before as we went through it, while also adding a few additional items of information. He hopes to attend the event.

#### **Validation of Themes: Yes**

**Issues:** Due to his loss of consciousness while in the ED, Alan was quite reticent to select themes. However, when I explained how his specific experiences fit in to these, and that there were wider systems issues and lessons he felt more comfortable to do so.

#### **Selection of Improvement Priorities: Yes**

**Issues:** As above. Alan does not remember the ED but his overall trip, and the fact that he had excellent medical care when he could not self-advocate demonstrate a positive factor of the system.

#### **Release Form Signed: Yes**

**Issues:** N/A

The difficulty in making the selection was a significant one in relation to the methodology, particularly where participants did not feel they were equipped to make the decision. EBCD is by design a collaborative process that focuses on drawing patients and carers into ownership of service redesign. The challenges of recruiting and facilitating ownership of research with non-palliative patients have been discussed earlier (Coulter, 2011), but these challenges are magnified with the palliative population. The validation and selection process had been adapted to ensure that this group had full access to, and ownership of the stories and experiences they had shared.

In the case of Ron and Jean, both were initially unwilling to make the selection, saying they felt that the choices of the facilitator would be fine. Their response may be linked to traditional medical healthcare model still prevalent in palliative care discussed in Chapter Three, which operates within a paternalistic epistemology and ontology.

During her interview, Angela, 66 summed up why some of the older participants might struggle to take ownership of their own care, and by extension, the service redesign priorities:

*'...I think it's probably a generational thing too. I mean I'm fairly elderly, but I think too that, especially if you're, say 20 years older than me, which would bring you up to 86, that it's like um teachers and the police and medical people that you, you don't challenge, you don't ask, you just leave it to them because they know but I think that's very much changing and that people do challenge and ask and I think that's quite right and proper and after all, you know, they're only human, they're doing a job, just like us all...'*

Angela, Interview 4

### ***Challenges in the process: death of a participant***

One of the concerns already highlighted when working with palliative care patients is that they may not live through the whole process. Sadly this was a reality for this thesis. I learned that one of the participants had died just days earlier. The critical reflection discusses this in more detail. In relation to the study the spouse of the participant felt it was important to honour their wish to have been in the research and share their story. The participant's spouse therefore provided consent for use of their data, and provided validation and theme selection as a proxy as per the study protocol. Figure 54 contains an extract from the field notes made following this encounter, edited to preserve the confidentiality of the participant and their spouse.

**Figure 54: Edited extract from validation log**

I spent about an hour at their home. The participant died last week and so I was very careful to make sure the spouse was still willing to speak to me, and to check that they were ok while we were speaking. We did not read aloud the quotes I wished to use because it proved too painful, instead I outlined what the experiences were, what this meant for the research, and how it would be used. I also was able to explain some of the medical terminology, and explain some of the processes which they had not understood.

This was a very sad case, particularly in the light of the participant's very quick deterioration and decline (two months from the second A&E visit, three from the first). The study policy and protocol are set up to cover this potential occurrence and so the spouse signed off the form on behalf of the participant. I outlined everything clearly; they were fully informed of the study intent and use of the data.

The spouse said they were glad and keen to keep the data in the study and that their story be used in this way. They said if the study had been important to the participant then it was so to the spouse.

### *Discussion of selected improvement priorities*

The ranking selected by the patients and carers excluded Acknowledgement and Validation from the top three improvement priorities, which was unexpected as immersion in the data had led to this being considered one of the most important and impactful themes. It is possible that this improvement priority did not stand out to participants in the same way as it did to those reviewing the data externally (the facilitator and film editor) because participants were only reviewing their own data. Had it been possible to hold the shared feedback event there might have been a different outcome.

Similarly to the staff validation process which saw ‘Palliative Care’ included as a fourth improvement priority, the decision was made following the patient and carer process to include Acknowledgement and Validation in the DVD. The decision was based on the same rationale as before; in the capacity of facilitator certain observations and links had been made about factors that were significantly impacting on the quality of experiences. Without including Acknowledgement and Validation, any improvement strategies based on the other three improvement priorities had the potential to lose sight of the personal narrative of the patients and carers needing care from the ED.

The following section discusses the improvement priorities selected, exploring what they meant across the different experiences.

### *Improvement priority: Communication and Information*

Similarly to the two papers identified in Chapter Two exploring palliative care patients’ experiences in the ED (Smith et al., 2010a, Grudzen et al., 2011c), the staff data and the work at Mount Sinai, ‘Communication and Information’ featured prominently as touch points for positive or negative experiences in the ED. Staff had accurately perceived this to be a central issue for patients and carers who ranked it as the most important improvement priority (Table 18). Within the data, communication referred to interactions between staff and the patient or carer, between the patient and their carer, or between staff and other patients. Often the communication was about sharing information and the way in which this was or was not done. When reflecting on positive experiences participants could identify touch points directly resulting from what they felt had been good communication of information:

*'...people were very kind and very helpful and kept me informed the whole time and apologised when they hurt me. But, you know, in these situations, you're in the best possible place and you just go with the flow, and as long as the information is coming through, people tell you what they're doing, you know, it's fine... the people looking after me and the questions they were asking me and I felt very happy to ask them questions and I seemed to get the right answers and I understood what they were saying...'*

Angela (patient), Interview 4

Conversely, where patients and carers had been affected negatively by their experience it could often be traced back to communication of information:

*'...when you're in an emergency room well then you are assuming that something's gonna happen in there and then of course you've gotta go and wait and then be clerked in again and then you're asked again, what's the matter, what's wrong, why are you here, why, why have you been admitted today, why do you think you need, why are we now telling somebody on a ward this who then will get a senior person and then they will come and ask us again and I know the importance of the information, the record keeping, but I do question how many times if you're terminal you have to be asked certain questions, and there must be a better format of, of recording, record keeping...'*

Ann (carer), Interview 1

*'...You was just left there standing like you was nothing, a statue. You wasn't asked what your name was, what your relationship was to the person, nothing. You just stood there and then they would decide, when they took my husband off the trolley and put him on to another trolley and I kept saying to them like, he's lost so much weight, he's only seven stone, they're going to really hurt him by even lifting him, he's so weak. They didn't really seem to care. They just put him on the trolley, left him there and I was the one who had to organise if he was all right and look after him...resuscitation took over again...But I mean, they really reassured me, all the way through that if he did die, he was in the like correct place and they could give him everything that was going to be good for him...'*

Barbara (carer), Interview 10

### *Improvement priority: Systems and Processes*

In Chapter Four, Stage 2 had seen staff identify systems and processes as one of their greatest challenges to the provision of palliative care. Staff were again correct in their recognition of this same theme impacting on the experiences of the patients and carers, who had ranked it as the second most important improvement priority. The analysis of the patient and carer interviews revealed some of the challenges as they move within the wider system of the NHS and its many smaller systems, for example the GP, community services and the ED. Even within these smaller systems there exist micro cultures; mini worlds that have their own specific process and environment. The work at Mount Sinai aimed to reduce these micro cultures by customising various processes, improving transitions within the ED and between departments for the patients and carers. The following three quotes demonstrate how different systems and processes within the ED can impact negatively on patients and carers and why they selected this as an improvement priority:

*‘...we had a very, very sick man who was terminal and he’s lying on a trolley in A&E and there must be a different route for this...there must be an area where they sit people who are requiring palliative care in all its format and, and the staff were not able to provide that cos they were not there necessarily to provide that...’*

Ann (carer), Interview 1

*‘...I was then given some meds, but I had to go down and actually this was...the most off-putting part of the day. So it was about quarter to 10 in the evening [Angela had been in the ED since 10am that morning], by this time and I had to go down to the pharmacy, which of course was closed, so there was just a little window which you had to put your prescriptions through to the pharmacist and then the waiting area was practically in the dark and it was and then there was an open corridor down the side of it and I waited for about 20 minutes and the pharmacist came back and said she was terribly sorry, but she couldn’t understand what the doctor had written and she was trying to locate him but he was on a break. Would I mind coming back in the morning. I said, no, I want to take it tonight, I want to start this stuff tonight and I’ve had a long day and I really want to go home and not have to come back here tomorrow...’*

Angela (patient), Interview 4

*'...there's no system. And it's not the nurses, they just haven't got time. They're bombarded with paperwork, they're bombarded with getting from A to B as fast as possible and in the meantime there's a patient laying there, that's got a heart, a mind, a soul, a body. But they don't see that part of it. I don't think they can see that part no more. That part is missing. It's missing from the picture...That's what they forget about and that's the most important thing, the patient and the relative because it's the relative that takes all the pressure and everything from the patient. So if the relative can't be reassured, how can they reassure a patient? They can't do it, you can't do it...'*

Barbara (carer), Interview 10

### *Improvement priority: Changing Expectations*

The third improvement priority selected by participants was changing expectations. Throughout the interviews it was evident that these older palliative care patients and their carers were living in a state of fluctuation. They were experiencing changes and deterioration in their conditions that called for emergency care. However, their individual stories revealed a shared narrative in the ED that was also reflected in literature from Chapter Two; patients and carers were acutely aware of their needs, but also aware that the ED was not always equipped to provide for them (Grudzen et al., 2010, Kompanje, 2010, Gardiner, 2011). The following three quotes show the participants expressing their concerns about the current system's ability to provide palliative care for their changeable conditions which they themselves were not always sure how to manage, and why this was selected as an area requiring service redesign:

*'...you're grateful for the fact that you were getting the appropriate care for the condition in the wrong environment...so then it doesn't feel as appropriate because you're not in the right environment to receive it, so your expectations are changing all the time...'*

Ann (carer), Interview 1

*'...and we're all getting older and your problem is going to be compounded by the fact there's going to be so many of us....Because there are so many different forms of illness and immobility now, that it's impossible really. I mean, for somebody like you the problem must be enormous...'*

Ron (carer), Interview 2

*‘...Older doctor has treat several different type of patient, so he got more practical knowledge about more patients than young doctor...medical knowledge nowadays getting more and more so it is advantage for both young and older doctor to learn something new...’*

Manubhai (patient), Interview 8

#### *Improvement priority: Acknowledgement and Validation*

Acknowledgement and validation had been identified and classified as a theme based on the quality of the ED experience described by the patients and carers. It referred to descriptions by patients and carers of how they felt staff related to and cared for them. How staff did or did not express their understanding of the individual needs and the impact the experience was having on patients and carers in the ED had stood out as being a major touch point. Indeed it seemed to correlate directly to the ED experience being remembered positively or negatively. The three quotes provided below demonstrate why this theme was considered significant to the perceived quality of the ED experience:

*‘...nobody asked us [Ann and her husband] anything about our thoughts, about how do we want the treatment, where do we want the treatment to take place...I knew that to get him home this was the way we’d do it and they were doing the best they could but...no one really asked... in A&E how are you doing with all of this, how are you coping, this is your third time you’ve come in, how do you feel, is there anybody at home for you, or nothing like that...’*

Ann (carer), Interview 1

*‘...Jean [Ron’s wife] is very unstable on her feet, she has no balance, so she has to be guided and led and held up and she totally lacks confidence because things that should work don’t work... wherever we go, we lead her...But the idea is, I now know what I have to do and we do it quite well...she knows what she’s got to do with me, but when it’s somebody else, she suddenly loses complete confidence cos she doesn’t know where to go. She can’t see... it’s a system that we’ve got used to and it fits her particular predicament. Now if anyone else comes in it goes haywire because she doesn’t know where things are and she can’t trust anybody else...’*

Ron (carer), Interview 2

The third of these quotes refers to Heather’s experience of being in the ED by herself, lying on the trolley, feeling unseen and struggling to ask for help:



*‘...Just lying there, just on my own and just watching people walking by and by and that was it. That was all, but as I said, if I didn’t ask for the cheese sandwich and the cup of tea, I wouldn’t have got one at all. And I hated asking them cos I knew they were busy...I didn’t really want it but I was just really hungry, I was sick with hunger. Cos I don’t think I had any breakfast that morning, when I come to think of it and I think she made me a cup of tea. But I felt embarrassed asking for it. It’s not as if they came round and said, would you like a cup of tea or a cup of coffee or anything. I felt embarrassed that I had to ask. But I felt sick that I thought I’ve got to ask for something, for something to drink or. Didn’t even ask if I wanted some cold water or anything. It’s just like you’re laying there, that’s that. And I hated going in the second time cos I thought they’d do it again to me...’*

Heather (patient), Interview 5

The final patient and carer improvement priority differed slightly from the perceptions and expectations of the ED staff obtained in the feedback event in Chapter Four. In the staff ranking discussed in Chapter Four, the priority that staff felt would be the most important theme for patients and carers was ‘lack of staff time to attend their needs’. This title had been drawn from experiences within the staff interviews and is in many ways encapsulated within the patient and carer improvement priority ‘Acknowledgement and Validation’. Table 19, presenting these different perceptions, shows that there was some overlap and accurate understanding from ED staff and the researcher, but that the patients and carers were more concerned about their own personal changing worlds than had been anticipated or understood.

**Table 19: Variations in perceptions of patient and carer improvement priorities**

<b>Researcher’s perception</b>	<b>ED staff perception</b>	<b>Patient and carer perception</b>
Acknowledgement and validation	Lack of staff time to attend to their needs	Communication and Information
Communication and information	Poor communication between ED and other services	Systems and Process
Systems and process	Inefficient systems and processes	Changing Cultures (Expectations)

#### **6.7.6 Frame 6: Creating the trigger film for the co-design event**

Once the improvement priorities had been selected by the participants, the quotes within the tables of analysis shown in Frame 4 were reviewed with the film editor to identify how the shared story should be presented. The participants had given their permission to use and edit

the quotes and stated they felt comfortable that their experiences would be represented accurately. Conducting this process with the film editor who has experience of making health care films was immensely valuable. It provided a space to discuss the data and deliberate over which quotes best exemplified the improvement priorities. Although there were possibilities at this stage that the DVD could later be used for training purposes, its primary function was to act as a trigger for discussion in the co-design event. This helped with the quote selection process as it gave a clear focus.

Across the ten interviews the experiences and memories of the participants of the ED varied considerably, despite the correlations within the improvement priorities. Initially the first version of the DVD contained quotes from all ten interviews. The film was then reviewed by the thesis supervisors who provided an insightful perspective about the management of the study data. Their suggestion was that only the most pertinent quotes needed to be included in the DVD based on its purpose as a trigger for discussion. The long-term plans for this work, discussed further in the Epilogue, meant that all experiences would still be used. Following this review the following changes were made to the patient and carer film that was shown at the co-design event:

- Re-phrasing the improvement priorities to make them less clinical and more approachable to those outside of the medical field as follows:
  - Improvement Priority 1 Systems and Processes renamed: Finding our way
  - Improvement Priority 2 Communication and Information renamed: Knowing what is happening
  - Improvement Priority 3 Acknowledgement and Validation renamed: Seeing the person in the patient
  - Improvement Priority 4 Changing Expectations (formerly changing cultures) renamed: Expectations of care
- Reorganising certain quotes within the improvement priorities so they follow the story of the movement of the patients and carers into and through the ED.
- Removing several quotes that did not clearly tie in the narrative or succinctly express the themes.

The reframing of the improvement priorities was an important process as it breathed life back into what comparatively read as quite stiff and stale jargon. Frame 6 in Chapter 4 stated that at this point the names of staff themes were reassessed. Frame 5 showed the overlap between the staff and patient-carer experiences. This made reframing the staff improvement priority to reflect this overlap a logical step. Table 20 contains the reframed improvement priorities for both groups. They are shown together to demonstrate the close relationship in their experiences and preferences for change. This thread is continued in Chapter Seven in regards to how the shared experiences influenced and impacted upon the co-design event.

**Table 20: Reframed staff and patient-carer improvement priorities**

Staff priorities	Patients and carers priorities
Helping patients and carers find their way	Finding our way
Being informed and informing patients and carers	Knowing what's happening
Seeing the person in the patient	Seeing the person in the patient
Expectations of the care we can give	Expectations of care

The suggestion from the supervisors, of removing some of the interview clips was a challenging one, as it meant that some participants had very little or no exposure of their story on the DVD. Shakuntla (the carer), had not been in the ED with Manubhai. Shakuntla had been affected by his frequent ED admissions and was pivotal in ensuring he got the medical aid he required. Her data provided evidence into the how simple things like a phone call from the ED could help reassure the carer and the patient, maintaining their communication; a touch point discussed in Frame 5. However, Shakuntla's English was not always clear enough for her experiences to be easily captured in small sound bites and woven into the narrative of the film.

Alan's interview also presented complications. He had been unconscious for the duration of his ED visit although his son was present. Regrettably it was not possible to interview his son. Despite this, there was still valuable data in the experiences that Alan had been willing to share. Alan felt that the care provided to him in the ED had been 'appropriate' and his son had commented on how well he had been looked after. Alan's insight was very useful when looking at how patients are moved on from the ED and if they are ever informed of what happened to them while they were unconscious. His data provided a perspective into the care post-ED, in the hospital and then the discharge home. His discharge process had been poor and had caused a relapse that he felt undermined all the excellent support provided as an

inpatient. His story added to the understanding of the variety of experiences and reasons a palliative care patient might use the ED. However, his interview data was largely unsuitable for the DVD and its use as a discussion trigger. Alan did attend the co-design event, providing on-going insight into the patient perspective of the themes identified by patients and carers and staff (Chapter Seven).

Fred and Manubhai's interviews were quite similar in that they had ED experiences that were unremarkable to them in the overall context of their interactions with the NHS. Both were positive but there were limited sound bites clearly expressing the touch points of why they were positive and what they were expecting. Alan, Fred and Manubhai's experiences were therefore termed as 'neutral' based on these factors.

During Frame 5 discussions with participants had included the use of data in the DVD, including highlighting that some interviews might have less exposure. It was emphasised that the DVD was only one output of the project and participants were assured that all data would be used more widely to inform teaching and future research. The insight of Shakuntla and Alan for example, provide constructive data as to the role of the ED within the wider healthcare system. Therefore, although ideally all participants would have had equal exposure, to create a useful and coherent film these edits needed to be made.

The final film was 27 minutes and 30 seconds long. It was divided into the four improvement priorities, each approximately six to seven minutes long. The DVD began with an explanation of the research and a quote taken from the interview with Ann where she stated why she was keen to participate in the research. It concluded with an acknowledgement of thanks to all the patients, carers and staff for their input and releasing their data. An e-mail account was opened retrospectively to manage any queries or inquiries about the film were it to be used for teaching or other dissemination activities. The final film that accompanies this thesis was edited further following the co-design event, discussed further in the remaining chapters.

## **6.8 Critical reflection**

Having undertaken and completed Stage 3 of the EBCD process with all of the adaptations and challenges, I found a lot to reflect upon. Predominantly I considered my own conduct in these processes, as well as the implications of the adaptations for the thesis. In the follow

sections I offer my critique of these different aspects, moving through the processes in the same chronological format as the main chapter.

### **Recruitment**

Re-entering the ED to recruit patients evoked similar nerves that I faced early on in Stage 2 while recruiting staff to participate, despite being in the ED occasionally for teaching and updating people on the progress of the work. However, staff were friendly and supportive and I quickly relaxed into the role, enjoying being back in the clinical environment. This time in the ED offered me a non-threatening environment to establish relationships and talk in more detail with newer staff members, or staff who I had not previously been able to speak to about their experiences of palliative care patients and carers. The extract from Log 1: patient and carer interviews (Figure 42) shown previously in the chapter reflected on these interactions. These interactions reinforced the improvement priorities selected previously by staff, as I heard similar stories, confusion over identifying palliative care patients, and struggles with working with services outside of the ED.

Although physically exhausting, the recruitment stage in the ED was manageable because it was familiar. The remainder of Stage 3 of the EBCD process became more challenging on a personal level as it progressed. The traditional risks to the researcher while conducting lone data collection consider personal safety. The ethics application outlined a strategy to manage potential safety risks for carrying out data collection at people's homes rather than in a public space as per King's College London guidelines.

I gave a list of addresses, names and contact details of participants to the lead supervisor prior to the interviews being conducted. She was contacted by phone on arrival at the data collection site and when leaving. In the event that I was unable to contact the lead supervisor within the set time frame she would undertake the necessary steps to follow up and ensure my safety. In practice the visits were safely conducted, although the issue of psychological risk to the 'lone researcher' was not considered until the interviews were underway. I had been careful to ensure that my training and research competence meant that the conduct of the interviews would be as easy as possible for the participants with minimal distress: I undertook the Good Clinical Practice training; I spent time talking with the EBCD researcher and learning from their practical experience of carrying out interviews with breast and lung cancer patients; I was familiar with the research environment, and by this stage I had the full support and backing of the ED; I had conducted home visits to patients while nursing and I

am a trained palliative care nurse. Equipped with these factors I started the recruitment and data collection processes confident that I could respond to challenges professionally; where situations arose that were beyond my competency I had the support of my supervisors, peer support and the clinical lead to turn to. What I had failed to anticipate, and discuss further later, was the impact this stage would have on me.

### **Data collection - weaknesses**

A weakness in the data collection was the non-participant observation in the ED. I found returning to the ED for prolonged periods a complex experience as I was now in the role of an observer and researcher, but my training and instinct was as a nurse. I had also worked clinically in the ED which, on reflection, I realised meant that I was not able to see things as objectively as anticipated. During the data collection at Mount Sinai I was comfortable being in the department as EDs tend to be very similar in nature, but there was also enough unfamiliarity that I could see things with ‘fresh’ eyes. At St Thomas’ it was challenging to stay silent and just observe practice as staff would talk with me, and my instinct was to be part of the environment. This was a failing in the quality of the observational field notes. It was only with hindsight as I heard the patient stories that I was able to recognise nuances that are common place or second nature to a staff member, but starkly distressing for a patient or carer. Staff assumed that patients would be distressed by other patients, but as the discussion in Frame 5 showed, patients and carers expected this. They were more distressed by what they took to be a lack of kindness or side-lining by staff in their business.

### **Data collection - challenges**

An on-going challenge in the data collection was that of understanding my role as a researcher, rather than as a nurse. Figure 44, presented earlier in the chapter, discussed an interview that was scheduled to take place but which was cancelled on arrival at the participant’s home, in agreement with the participant. The reflection showed that I had said the gentleman would be welcome to telephone me. At the time I had thought nothing of this remark. I had been distressed by his experience and his sadness and my instinct as a nurse was to offer support. In supervisory reflection the error of this action was pointed out. It had overstepped the researcher-participant relationship boundary and had offered something that I could not feasibly sustain had he then made contact. I was asked to consider the burden that I would be assuming, particularly if I had gone on to make the same offer to other participants. It was not sustainable, and although triggered by concern, it breached the remit of my role, capacity and ethical boundaries. As it transpired, I had not yet given the gentleman my

contact details and so the relationship could not progress. This incident served as a caution and I was meticulous in monitoring and reflecting on the relationships that were forged with the rest of the participants.

At times however, I became almost paranoid that I would inadvertently overstep a boundary and jeopardise the integrity of the research. For example I met with Ron and Jean at St Thomas' Hospital following their interview to give back the interview transcript and set a date for the feedback. They gave me a small package and said it was a little present. Figure 55 presents this account with my concerns and reflection.

**Figure 55: Extract from 'General data collection log: Ron and Jean'**

Today I met with a couple whom I had recently interviewed, to return the transcript to them for their review (Ron and Jean). They handed me a small plastic bag and said 'this is a little present; don't open it till you get home'. I was completely taken aback and shocked as, out of all the scenarios I have tried to prepare for, it never occurred to me that people would give researchers a gift. At the time I was very uncertain and took it saying thank you. Our meeting wasn't long and I left shortly afterwards. They also offered me a place to come and stay should I wish to if I needed a break. I was also not really prepared for this but due to recent reflections on boundaries and relationships with participants I was more equipped to say thank you but no, the next time I will be in touch will be with the analysis (See Day 10 & 14, Log 2, and interviews 2/3 and semi-interview, Log 3). As I walked back to work from the hospital I considered what I should have said and done, which was to say 'Thank you so much for being so kind and thoughtful, however, I am ethically bound and not allowed to accept any gift. I do appreciate the very kind thought and I'm sorry I must decline'. As it transpired they gave me a small pack of millionaire shortbread because that is what they had out when I did the interview and I had said I really enjoy it. They also gave me a little card wishing me every success in my project. This actually feels like something I can reasonably accept on this occasion. However, I am more equipped and prepared should something like this occur again.

### **Data collection – managing and coping**

Following the incident with the gentleman who was not interviewed, I was asked by the primary supervisor if I would like to meet with a counsellor to talk through some of the challenges I was facing. By this stage I was starting to contact potential participants on a daily basis and carrying out the interviews. Participants often shared details outside of their ED visit that were at times deeply distressing to hear. In addition I was still recruiting and had heard that some of the people I had met in the ED had since died. I was managing the study alone and the ethical guidelines meant that I could not share the details of the interactions that were causing me distress with my usual support network, such as my family.

The counselling sessions were provided by an experienced nurse and counsellor based at King's College London. They proved to be a useful way of identifying the root cause for the

interactions that were distressing, for example not being able to nurse people. The sessions gave a space to consider the impact of the research. One challenge discussed regarded hearing negative experiences from participants and having to resist the instinct to offer nursing support and advice. Constantly monitoring practice and boundaries of my the role as the researcher/facilitator to separate them from my nursing instincts was at times tormenting and a heavy dichotomy to manage.

This is not an unfamiliar challenge and as I made my ontological and epistemological stance clear in the prologue, it was this stage of the EBCD process that demonstrated I should also have considered my professional stance. Other nurse researchers have also struggled to find a balance in this dual role and dual perception (Bailey, 2007). The most honest response, even at this late stage, is to acknowledge that although my role and ethical approvals gave me the boundaries of a researcher, at my core I am a nurse. Although my gut instinct is to help, to find solutions, pathways, guidance and foster hope, I have tried to manage this within the confines of research. The following two experiences exemplified the challenges in finding my role and boundaries when faced with real life situations. Both have been anonymised as they contain sensitive material shared by the participants involved.

The first concerns an interview with a participant, who during the interview shared their thoughts of suicide based on their situation. I encouraged them to talk to their GP about their concerns but they shared that they had raised them before but had been told they had a lot to live for and wouldn't do it. Throughout all of their experiences they had struggled with healthcare professionals treating them dismissively and having to fight for the care that was needed. Listening to their words and concerns I felt that my duty of care rested in showing that I had heard what they had said. I chose to share a small piece of personal information with a perspective I had gained from it. This seemed to resonate with them and after a short pause they began to reflect in a different way, saying they were feeling different and better. As I left they said they felt they could see the sun again which; an unexpected but encouraging outcome. In total I was with them for five hours. I came away exhausted but feeling that this had been the right thing to do. I spoke with my supervisors and the counsellor immediately on my return to discuss the incident and how I should proceed as I still had concerns for the wellbeing of the participant despite their positive attitude when I left. I knew that it was not appropriate or manageable to develop a supportive relationship but ethically I felt I needed to follow up with them after the interview given how intense it had been. This was on the Friday and so I waited until the Monday to give both of us time to rest and reflect.



They still sounded positive and thanked me again for what I had said and for listening to them.

The final incident that impacted upon me during this stage was when I heard that one of the participants had died. When I visited their spouse to feedback the analysis, they shared with me their concerns over the medical care given in the ED and questioned if the participant had been misdiagnosed on the first visit. I had similar concerns based on the information provided in the interview and I worried there had been a misdiagnosis as a result of poor practice. The ethical application stated that in this event the situation would be fed back to the clinical lead for investigation. The spouse was considering making a complaint to the ED, but when I said that I was also planning to approach the ED to request they review the case, the spouse chose not to. In consultation with the study supervisors I reported the case to the clinical lead who followed it up in detail and we met to review the medical notes and transcript. As it transpired the medical management had not been at fault, but it was evident that the communication to the couple about the diagnosis and treatment had been poor in the ED as well as in other care settings. In addition, although the medical assessments and clinical treatment in the ED were well documented and appeared appropriate, the reports of several staff encounters in the interview had frequently caused distress and added to their confusion. The clinical lead followed the case up with the participant's GP and was willing to meet with the spouse to discuss the care if they wished to. I fed back what had happened to the spouse who felt that they wanted to leave things as they were for the time being, but said that what I had done had been greatly appreciated.

Although the follow up of this case was within the remit of the study protocol and my conduct was within the role of a researcher, I found this process particularly challenging. I was concerned for the spouse, upset by the participant's death, and also apprehensive about managing a good relationship with the research site. In addition I was concurrently handling the on-going data analysis, validation, feedback and preparation for the co-design event.

### **Questioning the 'self' within the process**

The outcome for both of these situations was as positive as could be hoped for, but Stage 3 was the most personally impactful and challenging stage of the research to date. It caused me to question myself, my role and my understanding of clinical practice as I knew it. My identity was challenged and my second nature nursing instincts had to be silenced to preserve the honesty of the data and the relationships with patients and carers. It was often sad and

lonely as well intense. The intensity was increased by the tight time frame I was operating under which, despite the counselling sessions, gave little time to reflect or process what I was feeling.

Despite this, Stage 3 also forced the greatest growth, both as a researcher and personally. I was surprised at my own capacity to respond to the stories shared by participants, and their feedback stated they had felt heard and cared for even though I was unable to 'nurse' them. I was able to form trusting empathetic relationships in the capacity of a researcher in a very short space of time that resulted in valuable data collection. I was able to move further away from the paternalistic mind set I had started the research process with, and allow the research to develop and the narratives to emerge in the direction it needed to. It was also rewarding to meet the ten participants and spend time with them. I valued and appreciated their input and time despite the challenges.

Were this stage to be repeated, counselling would be a mandatory part of the process. I would also hesitate to conduct this work as a lone researcher as the emotional burden was at times devastating, despite my background in palliative care nursing. There were too many different factors to consider and manage at once. In particular, working alone without other researchers to analyse each step until the making of the DVD was isolating and slowed the progression of this study.

## **6.9 Conclusion**

Stage 3 of the EBCD process saw the patient and carer story emerge and the selection of improvement priorities that reflect those identified by staff in Stage 2. The next chapter pulls these two stories threads together in a co-design event, which sees the patients, carers and ED staff meet and collaboratively develop strategies for improving the experiences of palliative care in the ED.

## **CHAPTER SEVEN: THE SHARED STORY**

### **(The co-design event)**

#### **7.1 Introduction**

In this chapter the narrative reaches Stage 4 of the EBCD process, the co-design event. For this research project it was the pinnacle moment that all preceding chapters had been building to. Titled ‘The shared story’, this chapter explores the co-design event as the point at which the patients, carers and staff were able to come together in a safe environment to hear each other’s stories and capture their shared experiences.

In Stage 2 of the EBCD process ED staff met and worked together to discuss and select their improvement priorities for palliative care in the ED. Traditionally Stage 3 of EBCD projects sees patients and carers undertake the same processes concurrently in their own participant group (Piper et al., 2010c, Tsianakas et al., 2012, Bowen et al., 2013, Donetto et al., 2014). The previous chapter demonstrated why this was not possible in this study, presenting and appraising the alternative strategies used to gather the consensus on the improvement priorities to include in the film.

Stage 4 now marks the start of on-going collaborative working between the groups to design, develop, implement and review improvement strategies (Robert, 2013). The challenges for this thesis from the research environment and vulnerable patient participant group have been established. Their implication for Stage 4 was a lack of existing relationship between any of the parties involved, prior to the co-design event. The success of co-design efforts, particularly in such an emotive area as palliative care in the ED, rely on trusting relationships and mutual respect between the people involved (Hampson et al., 2013). It was therefore vital that the co-design event quickly fostered and established a safe and trusting environment for all the participants.

The following chapter offers a reflection on the full EBCD process undertaken for this study

#### **7.2 Chapter overview**

In this chapter the narrative is led through the chronological process of preparing for and conducting the co-event. The event is evaluated before a critical reflection of the process is given .

### **7.3 Purpose of the co-design event**

In Experience-based Co-design research, the ‘co’ is core to the conduct of the endeavour, placing patients, carers and healthcare staff in equal partnership with shared leadership (Bate and Robert, 2006). In all EBCD projects the co-design event marks the significant moment at which the participants come together, and experiences are jointly translated into potential improvements. For, as succinctly phrased by Tsianakas et al (2012): *‘Stories in themselves do not bring about change; it is the change process itself and the direct and active participation of staff and patient in it that produces implementation and action, and ultimately spread and sustainability’* (Tsianakas et al., 2012, p.2645).

### **7.4 Aims of the co-design event**

The event had four aims:

1. To agree the selection of improvement priorities by the participants.
2. Collaborative working to decide the ‘next steps’ in the redesign and implementation process.
3. Post-co-design event identification of potential design principles for delivering palliative care in the ED.
4. To inform the early stages of post-doctoral work continuing the development of palliative care in the ED.

The first two aims are discussed in detail this chapter as they are directly related to the research project. Aims three and four were part of the longer term plans for this work and were more concerned with the wider implications of this research for practice. This is to ensure the integrity of the methodology and the stance of this thesis which uses a narrative approach to tell the story of the study. The third and fourth aims are mentioned at this point to highlight when the data informing the conclusions provided in Chapter Eight were gathered. Chapter Eight allows the thesis to look beyond this small research study and into its implications for the methodology, practice and policy. However, it was important that the content of this chapter maintained the chronological retelling of this research project, thus concerning itself with exploring only the first two aims.

## **7.5 Preparing for the event**

Planning for the co-design event was originally intended to start once all data analysis and validation processes in Stage 3 had been completed. However, the death of one of the participants and re-hospitalisation of other patients and a carer re-emphasised their frailty. There was a degree of urgency that meant it was necessary to set a date and start planning for the event quickly to ensure that it was accessible to as many of this group as possible. The preparation for Stage 4 was therefore conducted concurrently with the validation and film making process of Stage 3.

### **7.5.1 Ethical considerations**

Ethics approval for the event had been granted under the application submitted in Stage 3 (Chapter Six). The main ethical concern regarded the potential risk for emotional distress to those attending. Although it was not anticipated that the co-design event would have any adverse effects on participants, facilitators, including trained and experienced EBCD researchers were present to guide the process (CD, BG and KL). Their input is discussed in the critical reflection at the end of this chapter. If ED staff had concerns following the event, the clinical lead and PDN planned to be present and available for support. Had there been concerns affecting patient and carer participants that were beyond the remit of the co-design event they were to be guided to either their GP for health related support, or to the complaints department at GSTT, as per the information sheet (Appendix 24).

In reality in the approach to the co-design event new strategies had to be formulated, as the clinical lead and PDN could not attend. This is discussed below.

The location of the co-design event was an important feature and a neutral location is generally recommended (The King's Fund, 2013a). At one stage the event was to be held in a conference room at GSTT to allow staff easy access. On reflection of the patient and carer data and in consideration of painful memories for those carers who had been bereaved, this was deemed unsuitable. It was also possible that being in the hospital environment could work against establishing a safe and shared atmosphere for all participants. A neutral location within five minutes walking distance of the hospital with good travel access for patient and carer participants was then identified. The close proximity also meant that staff could attend if released from their shift. The ED kindly covered the costs of booking the room and funding from the PhD studentship provided for catering.

On enquiry the location had only one date available within the required time frame of the project; three weeks from the booking date. This placed considerable challenges on the planning of the event and conclusion of the data analysis, as well potentially limiting the amount of staff who could attend. The unstable condition of the patients was the driving factor and so the date was accepted. A room was booked that catered for twenty five people, allowing space in case all ten patient and carer participants attended (including the spouse of the participant who had died), plus ten staff members, and facilitators.

Co-design events usually run for three hours to allow people to watch the film and take their time over the discussion and selection of shared improvement priorities (The King's Fund, 2013b). This length of time was not feasible for the patient group given the frailty of many of them. Therefore, in consultation with the study supervisors and other EBCD researchers, the event and designed to run over two hours and fifteen minutes.

Invitations to the event were first offered to the patients and carers as it was important to know how many were able to attend. This was to ensure that the patient, carer and staff numbers were equal and that no one felt marginalised. Patients were initially invited informally over the telephone to gauge the numbers attending. If they accepted, a formal invitation was sent out containing:

- The information form (Appendix 24)
- An extract highlighting the co-design event (Appendix 25)
- An invitation with the location and map (Appendix 26 and 27).

Creating all of these documents and confirming the details took a week, leaving only two weeks to give staff notice. Staff were given a copy of the invitation and an information sheet about the event (Appendix 28). The critical reflection discusses the impact of the rushed nature of the preparation on the event.

The clinical lead and PDN had been informed on the day of the booking and regrettably neither could attend as there was an ED development activity that required their presence on the same day. They were able to recruit other senior staff in their place, but the staff rota could not be changed by this point, prohibiting some staff members who had been keenly involved and interested in the project from attending.

Prior to the event twenty two people were set to attend:

- Eight of the patient and carer participants
- Six ED staff members
- Representation from three members of the ED Transformation Team (the team responsible for leading the re-design work in the ED who were only introduced to the researcher at this point in the study)
- Three facilitators to help support small group discussion (The King's Fund, 2013a):
  - The lead facilitator, CD, who had run several co-design events previously
  - One of the study supervisors: KL
  - An external facilitator from Marie Curie: BG. BG had been part of previous co-design work and came to offer non-biased support and take notes
- A photographer, OS, to capture a visual record of the event that could be used for dissemination and reflection
- RB, the author of this thesis

### **7.5.2 Event preparation**

Once the outline and practicalities of the event had been decided, the structure and administration of the event was planned. Basic administration factors were prepared, such as name badges and consent forms (Appendix 29).

To gain consent for use of photographs taken during the event, coloured stickers were placed on name badges to indicate those willing to be photographed and those who declined. A red sticker indicated no photographs, and blue indicated permission to be photographed. A written record also documented this.

Patient and carer travel costs were to be provided for, although all declined this offer. Minor but significant details such as pens, post it notes and paper were also prepared for use in mapping and improvement priority selection activities (The King's Fund, 2013a).

The room itself was to be laid out in a 'small group' setting, with patients, carers, ED staff and members of the transformation team gathered in mixed groups around tables. On the day of the event the actual number attending was less than anticipated. To help facilitate a single group discussion the chairs were set out into a horseshoe shape (Figure 56).

**Figure 56: Layout of the room**



The conduct of the event was closely monitored with each section given a time frame. This was planned in consultation with CD and is discussed in the next section.

Planning the event also meant re-appraising the patient, carer and staff data to determine how best to present it to those attending. Revisiting the staff data and comparing it with the patient and carer data revealed a close relationship between their shared improvement priorities. This has been discussed, and Frame 6 of the staff analysis in Chapter Four detailed how the original staff priorities, which were prepared as a Power Point presentation for the event, were renamed to reflect this relationship more fully.

Previous EBCD projects have acknowledged that it can be challenging for staff to view feedback from patients and carers (The King's Fund, 2013b). The King's Fund EBCD Toolkit advises that the film be edited so as to facilitate group discussion and avoid personal agendas (The King's Fund, 2013b). Therefore data included in the film did not contain any opinions on specific staff, but rather was edited to show a shared story of moving through the ED with the aspects that improved or were detrimental to the experience highlighted. Examples included were generic and did not target any single staff member or encounter.

### **7.5.3 Preparing for the analysis**

The final element of planning concerned the analysis. The activities in the co-design event (shown below) meant that responses of the participants to the patient and carer and staff data were analysed immediately and collaboratively. Participants would then be led through a



process to identify shared improvement priorities, followed by group validation and planning into how to implement the next steps to start making changes. To facilitate this analysis, film evaluation forms (Appendices 30 and 31) and event evaluation forms (Appendix 32) that had been created and used in other EBCD co-design events were provided (Locock et al., 2014).

Using the same format for evaluation as in other EBCD projects was useful. The degree of adaptations necessary to facilitate involvement of the palliative care patient group, a complex and busy ED research site, and management of the study as a lone researcher, meant that the forms helped provide structure and consistency within the methodological approach.

## **7.6 Conduct of the event**

This section leads the narrative through a review of the conduct of Stage 4 of the EBCD process chronologically, drawing on the audit log and photographs of the day. The analysis of the event explores the implications and meaning in the content shared below.

### **7.6.1 Attendance**

Although twenty two people had agreed to attend, six of the patient and carer group withdrew, all due to ill-health and for some further re-hospitalisation. This left only one patient, Alan, and one carer, Barbara, as representatives of the patient and carer group. On the day of the event seventeen people instead of twenty two were expected, leading to the restructure of the layout of the room (Figure 56). However, of the six staff members who had planned to attend only four were present: one ED nurse, one ED GP trainee/senior registrar, the ED matron and a palliative care consultant. All three members of the transformation team were present, along with the four facilitators, CD, KL, BG, the photographer and the sole researcher, RB.

In total there were fourteen people at the event. The lack of patient and carer presence was noted in the evaluations forms and is discussed later in the chapter. Figure 57 presents extracts from the co-design event log, written immediately following the event, that reflect on how the issue of attendance was managed.

**Figure 57: Extracts on attendance from co-design event log**

**Challenges**

**Not all participants turning up, impact on the running of the co-design event:** I had planned to place the participants into small groups to encourage discussion. However, due to the smaller number, the lead facilitator, CD, advised that we set the room up as a horseshoe and have group discussion. Both the patient and carer had no trouble in speaking out, and all attendees spoke or contributed at some point.

**Lack of patient/carers representation:** This was unavoidable due to their conditions and inability to attend. Initially eight participants wanted to attend but cancelled in the days leading up to the event, and on the day of the event due to ill health. Although there was representation from one patient and one carer, it was commented on in the feedback that more would have balanced out the event and enhanced the discussion and development of improvement strategies.

**Small ED staff attendance:** Room availability was an issue when planning the event, as it needed to be close to when the patient/carers interviews first occurred so they were still alive and well enough to participate, but also with enough time in between to allow for analysis, validation, making of the film and preparing for the event. As it transpired the ED had an event on the day of the co-design event which prevented several senior staff from attending. The PDN, who had been a staunch supporter and key gatekeeper from the outset, left the ED in the week prior to the event for a year's leave. I really felt her absence as she was familiar with the project and had been incredibly helpful and supportive over the previous three years, inviting me in to give feedback and eventually asking me to teach palliative care sessions to the ED nurses. Her absence put additional pressure on the remaining PDNs and none of them were able to attend. The matron was present but he was unfamiliar with the specifics of the work and we had only really spoken twice prior to the event. Only one doctor was in attendance from the ED, a senior registrar, but she had attended a teaching session I had run and also supplied a very useful case note. A second doctor was supposed to attend but was absent on the day. From the palliative care team one of the consultants attended. She has had increasing involvement in the project over its progression and was well aware of the work, having been instrumental in pushing through some of the changes made previously in the ED on the basis of this work.

**Successes:**

**Attendance:** The reasons for non-attendance were ill-health or unavoidable work demands rather than lack of interest in the project. This was encouraging for the development of feedback, designing improvement priorities and recognising the acceptance of the work by the department.

### **7.6.2 Starting and running the co-design event**

Five minutes before the start of the event the building was evacuated due to a fire alarm. This meant the event started late and the time for discussion was reduced. One of the breaks was removed and the event ran slightly over time. People were still arriving while the building had been evacuated. This led to concerns about participants finding the co-design group, and the running of the event to time, for example, some of the staff attending were new to the project and had only communicated via e-mail prior to this point. These concerns are outlined in Figure 58 below, taken again from the co-design event log.

**Figure 58: Extracts on timing from the co-design event log**

**Fire alarm/welcoming participants:** This was an ‘unforeseen event’. Five minutes before the start of the event someone thought there was a fire in the building and pressed the alarm. The building was evacuated and about 150 people waited outside while the fire service checked it was safe to go back. I found this very distressing as I was concerned about the patient/carer participants arriving and waiting outside in the cold in the middle of November. Thankfully we were not waiting for too long and I was able to meet and find all of them.

**Timing:** The fire alarm delayed the start of the session by about fifteen minutes. Due to the ill-health of the patient group I had arranged a shorter session than most CDEs. I also included two breaks in case they felt tired or overwhelmed. As the session started late there was not as much time for discussion.

Figure 59 shows the crowd who were waiting and the challenge in trying to meet people while staying in a group and making introductions. An unexpected positive outcome of the fire alarm was that it served to break some of the nervous tension between individuals who had never met before, and fostered a sense of camaraderie. On re-entering the building people were making conversation and the atmosphere was much lighter (Figure 60).

**Figure 59: Trying to meet co-design attendees during the fire alarm building evacuation**



**Figure 60: Re-entering the building**



### **7.6.3 Feeding back the data**

One of the challenges of feeding back the data was that the staff improvement priorities were shown as a Power Point presentation which lacked the power of the patient-carer film (Figure 61). The decision to not film staff was deliberate, but feedback of the event showed that those attending felt the staff voice was not given equal representation during this early stage of the co-design event. The next two sections of the chapter continue this discussion and show how the data were subsequently developed for on-going dissemination work.

**Figure 61: Feeding back the staff data**



One of the carers had been asked to introduce the film, and the PDN was going to present the staff presentation. They had been asked strategically, to reduce the voice of the facilitator and ensure that participants were telling their own stories during this important stage of the research. As the carer and PDN were unable to attend, this role was taken on by the researcher, which was a limitation of the event. N.B. Please watch the patient and carer sections of the DVD that accompanies this thesis at this stage.

#### **7.6.4 Facilitating discussion and relationships**

One of the researcher's concerns for the event was the speed at which trusting and open relationships needed to develop, enabling participants to feel confident and comfortable to share their reactions and state their views. Prior to the event effort had been taken to ensure that its purpose was clear, such as giving all participants an information sheet; talking with collaborators to explain its content and answering questions. At the event itself, the lead facilitator, CD opened with a clear introduction of its purpose. Throughout she presented probing questions to the group, ensuring that all voices were heard and valued equally. In addition, by using both discussion and evaluation forms it meant that collaborators were given different ways to reflect and share their opinions. As it transpired all collaborators present shared verbally and filled in the evaluation forms. Figure 62 contains a reflective extract from the co-design event log considering this element of the event.

**Figure 62: Extract on discussion facilitating from the co-design event log**

<p><b>Facilitation of the discussion:</b> The lead facilitator, CD, is an experienced co-design event facilitator and I was grateful to have her there so I could learn from her in order to run events in the future. During the event one of the participants spoke more than most of the others and it was difficult to know whether to interrupt or allow them the space. Had there been greater representation of patients/carers it may not have felt so unbalanced. Despite this, the comments and discussion was managed respectfully by everyone and some very helpful points were made.</p>
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#### **7.6.5 Reaction to the film**

Figure 63 presents an extract from the audit log that outlines some of the specific discussions that emerged after the film had been shown. Some of the staff were initially quite defensive, and the immediate atmosphere felt heavy. At times in the discussion the patient and carer perspectives were very different from the staff one. On these occasions the information gleaned through the non-participant observations was vital in providing background and context to some of the discussions. The observations proved to be useful in giving balance to the two perspectives of staff and patient-carer. This role at the event is discussed further in the critical reflection. Figure 63 presents an extract from the co-design event log giving more

detail on the type of challenges the collaborators had to work through together following the film.

**Figure 63: Extract on reaction to the film from the co-design event log**

**Reaction to the film:**

Due to the conditions of the patient group I had not screened the film before the event and I was quite nervous about the reactions. It clearly affected everyone in the room by the comments and their body language and expressions post-viewing. Initially the discussion was quite tense; the matron was quite defensive about the department and one of the patient/carer participants was quite critical. The matron made an interesting point that even if other patients *are* in the ED for drug or alcohol related issues, the ED have a duty of care to look after everyone with equal compassion and attention. The doctor tried to explain the challenge between majors and resuscitation, the different staffing levels, noise and demands making it easier to provide care in resuscitation than majors. However, the carer asked ‘are you saying you don’t have time to just put your hand on my shoulder and say “it’s ok”?’ This seemed to have quite a powerful impact. I was part of the discussion and drew out more points about the staff experience and the parallels between the two groups. I think it would be good to include the staff story into the film in some way as the patient film is so emotive and thought provoking compared to the staff power point presentation.

The participant collaborators had been given evaluation forms to document their reactions while watching the film (Appendices 30 and 31). These reflected the discussion and distress that some felt while watching the more negative experiences of care. These data are explored further in the next section.

### **7.6.6 Mapping the improvements**

Following the lunch break the group reassembled. The lead facilitator, CD, then led them through a mapping exercise to identify the shared improvement priorities and to begin planning the ‘next steps’ for starting to make changes. This was successfully and simply managed by asking two questions:

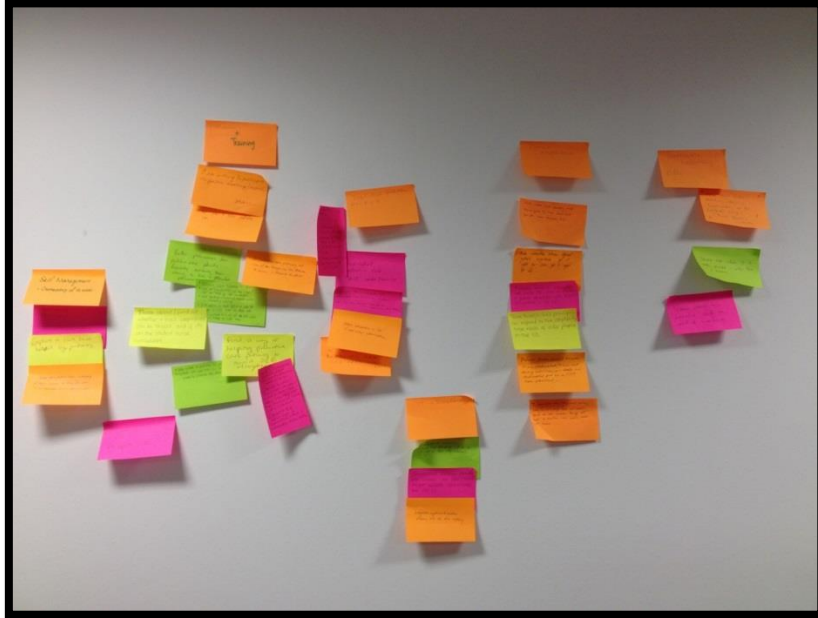
- 1) What can I or a person in this room do?
- 2) What big things need to be done by people/groups not in this room?

Collaborators were given post-it notes to write down their responses. These were then ‘mapped’ out onto a wall by the facilitators, revealing six priority areas for improvement:

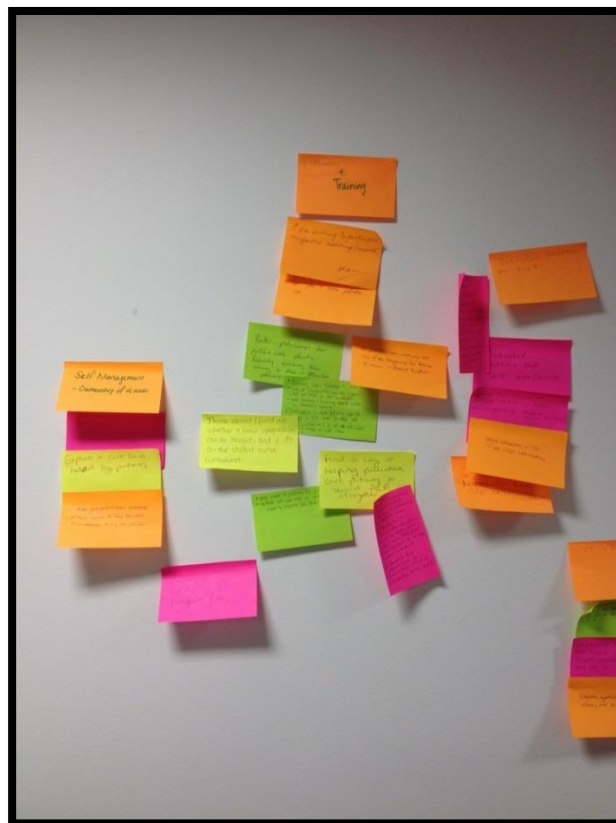
- 1) Self-management and ownership
- 2) Pathways and training
- 3) Dedicated palliative care space in the ED
- 4) IT and databases
- 5) Patient experience
- 6) Sharing the learning

Figures 64 and 65 show the post-it notes mapped out into themes which are analysed in the next section.

**Figure 64: Mapping exercise for improvement priorities**



**Figure 65: Mapping exercise for improvement priorities (2)**





### **7.6.7 Co-designing**

Once the mapping exercise was complete, the lead facilitator CD moved the discussion on to the 'next steps' in developing strategies to improve the identified gaps in practice. Initially it had not been certain that the event would be able to extend to this latter stage, particularly as there was not capacity to then hold the smaller working groups of Stage 5 of the EBCD process. However, the second discussion section had worked well to unite the collaborators and there was firm agreement that the areas selected needed development. The hospital-based collaborators present were also able to take suggestions back into the clinical area to raise them with managers and staff who could feasibly make changes.

The process of identifying the next steps was simple. The improvement priorities were listed out on flip chart paper and the lead facilitator CD asked those present what they would do to make changes in each. Again, it was not certain that people would actually volunteer or collaborate as the majority of people present were new to the project and had no pre-existing 'buy-in'. As it transpired, each staff member stated where they could make an impact on the improvement priorities raised. Their suggestions were discussed by those present, with different people offering suggestions, contact or to collaborate on the efforts, for example the ED palliative care link nurse and ED registrar/trainee GP volunteered to review and improve the route and care a palliative patient would experience through the ED. The palliative care consultant then offered to support them in this and to tie in the new process with the palliative care team. The name and 'next steps' were documented on the flip chart (Figure 66) and then e-mailed round to all collaborators after the event (Appendix 32). Chapter Eight contains reports on the developments that happened four months after the co-design event.



**Figure 66: Planning the next steps**

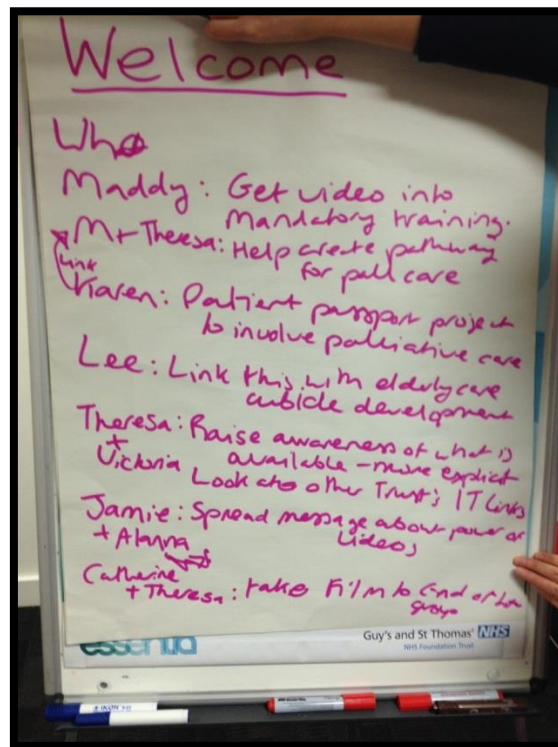


Figure 67 presents an extract from the co-design log which outlines the success of this element of the study. Despite the lack of knowledge about the study or previous collaborative working of those present, each person contributed to the process and expressed their intention of furthering the work. Again the critical reflection explores this in more detail, but as Figure 67 shows, Stage 4 of the EBCD process served to remove the researcher from being at the centre of the work, holding it together. Instead the data, findings and responsibility to make changes was taken up by those working in or around the ED.

**Figure 67: Extract reflecting on the co-design process from the co-design event log**

**Participation, where the ‘co’ finally happened:** Everyone present took part in the discussion, contributing to redesign strategies and all staff members left promising to undertake some form of work based on the outcomes of the session. These are recorded in the analysis documents in more detail. Throughout the project I have struggled with the lack of co-anything to the work, given the methodology design. However, at this stage I felt that the attending patient/carer, and staff at the trust, medical and transformation team alike came into and embraced the project. They worked and discussed redesign strategies and came out with practical solutions and assigned roles in a very short space of time. During the session, although I presented the findings and contributed to the first discussion, I did not feel that it was appropriate to say very much. And there really wasn’t very much for me to say as the findings I showed had a clear impact and inspired, at least intentions to change, although follow up work will demonstrate what actually happens. It was a very odd sensation to leave the event without a role for myself other than to begin to write up the event, feedback findings to those who had been unable to attend and, in a few months, follow up on improvement strategy development.

It is worth noting that, while feeding back the outcome to the patients and carers in the week after the co-design event who had been unable to attend, several offered to have on-going input into improvement work. Despite their absence from the event, they expressed that their participation in the earlier processes had fostered ownership and interest in being part of the change process.

#### **7.6.8 Concluding the event**

Once the co-design process had been concluded the collaborators were given a copy of the event evaluation form to complete. The lead facilitator, CD, and the researcher then closed the meeting, first asking if anyone had anything further to say and ensuring that everyone present felt that they had been heard. In response to this question people unexpectedly expressed their gratitude for the work, stating that the event, and in particular the film, had had an impact on them.

It was agreed that implementation would be followed up in about four to five months to inform the researcher of the progress, and that all collaborators, including the patients, carers and staff who could not be present, would be updated of the process. The feedback gathered from this follow up is shared in Chapter Eight.

The data gathered from the event to be carried into the analysis were:

- Film evaluation forms
- Themed post-it notes stating specific areas for improvement
- Notes taken during the event by the facilitator BG
- The list and contact details of those leading the ‘next steps’ for implementing aspects of the improvement priorities
- Photographs (shown throughout this chapter)
- Overall event evaluation forms

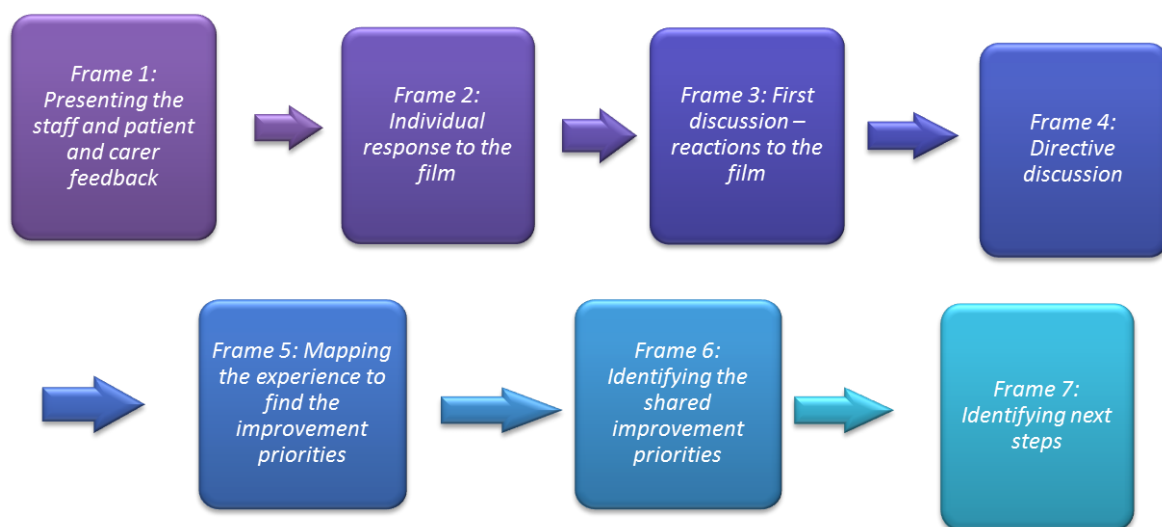
### **7.7 Findings of the event**

In this section the narrative leads the story on from the conduct of the co-design event to the analysis and presentation of the findings, demonstrating how the aims for the event were met. As stated previously, the first two aims are dealt with in this chapter:

1. The agreed selection of improvement priorities by the participants
2. Collaborative working to decide the 'next steps' in the redesign and implementation process

It took seven stages for the co-design event to meet aims 1 and 2. These stages, as with the former chapters, are presented as a series of frames (Figure 68). The frames are presented to allow discussion and reflection of the collaborative movement through the process of moving from the staff and patient-carer data to the improvement priorities and next steps.

**Figure 68: Meeting the aims of the co-design event**



Frames 1 to 5 present the processes leading up to the identification of the improvement priorities. Frame 6 presents the mapping activity and group analysis that identified six improvement priorities. Frame 7 deals with the identification of the next steps and who would be conducting them.

#### **7.7.1 Frame 1: Presenting the staff, patient and carer feedback**

The presentation of the staff, patient and carer data was discussed in the previous section. Sharing these data was the first step of the co-design process and required all the collaborators present to hear about both sides of the ED experience without making comment.

#### **7.7.2 Frame 2: Individual response to the film**

Figure 69-71 show the staff responses to their three questions on the form. The data in Figure 69 show that staff were quite shocked and affected by the film. It caused a strong reaction, and the range of experiences, as well as the impact of the ED visit on both the patient and carer, was recognised as an important factor to consider.

**Figure 69: Staff reaction to film evaluation form: Question 1**

<b>Your reactions to watching the film</b>	
<i>Staff member:</i>	<ul style="list-style-type: none"> <li>○ Nursing care <u>so</u> important – makes better impact than medical care</li> <li>○ Really shocking, as A&amp;E SNR nurse, that patient's telling stories of horrible experiences in A&amp;E: process breaks down for patients; explanations not given</li> <li>○ Also glad to hear that staff can be friendly and helpful as well and make pathway through A&amp;E quicker</li> <li>○ Upsetting to hear that Drs and nurses not giving proper explanation to family members</li> <li>○ Good to hear that some family members have had a positive experience</li> <li>○ Feels like 'basic care' has broken down</li> <li>○ Awful to hear family members feeling lack of compassion</li> </ul>
<i>Staff member:</i>	<ul style="list-style-type: none"> <li>○ V. effective way to portray range of experiences but similar themes around how difficult it can be to navigate A&amp;E</li> </ul>
<i>Staff member:</i>	<ul style="list-style-type: none"> <li>○ Want to continue to work hard to keep patients informed and improve patient care</li> <li>○ Appreciating it's the small things that matter</li> </ul>
<i>Staff member:</i>	<ul style="list-style-type: none"> <li>○ Good to hear it from patient/carer's perspective</li> <li>○ Saddened that we can't do it better</li> </ul>
<i>Staff member:</i>	<ul style="list-style-type: none"> <li>○ Important of relative/carer's experience of encounters within the ED</li> <li>○ Long term impact of bad experiences in the ED – <u>or</u> good experiences</li> </ul>

Figure 70 contains the responses from staff regarding their feelings on the film and if it represented their experiences. From the different comments which range from descriptions supporting the film evidence, to the simple '*sadly yes*' it was evident that the story shown by the patient and carers was regrettably recognised by staff. The answers focused on aspects of caring relating to patients and carers not feeling 'heard' or 'seen', and the challenges in having effective communication with vulnerable people in a busy and fraught environment.

**Figure 70: Staff reaction to film evaluation form: Question 2**

<b>Does it represent your experience as a healthcare professional?</b>	
<i>Staff member:</i>	<ul style="list-style-type: none"> <li>○ A&amp;E can forget to ask how loved ones are coping</li> <li>○ Patients aren't always informed of time frames – not explained when patient in A&amp;E</li> <li>○ Relate to staff having to deal with a palliative care patient &amp; then suddenly another type of patient in adjacent cubicle</li> <li>○ Patients don't always get offered comforting things e.g. cup of tea etc. Sometimes very focused on medical condition</li> <li>○ Relate to 'drug/alcohol' intoxicated patients get better attention than really sick patients</li> <li>○ Resuscitation does deliver better 1:1 care</li> <li>○ Drs and nurses (some of them) can be abrupt and forget to explain to patients and loved ones e.g. what's going on</li> <li>○ I can see how patients feel 'unheard'</li> <li>○ Not <u>all</u> patients have negative experience: it's so up to the staff on duty at that time</li> </ul>

- Difficult providing palliative care in A&E environment
- Staff member:*
  - Several themes in film that patients have told us matter to them, often very small:
    - Timely and accurate information
    - Discharge/transport done safely
    - Planning out-of-hours
    - Waiting about being told why/how long
    - Compassionate moments, time to care
- Staff member:*
  - Long waits can be real and are something we are constantly working on
  - Sometimes staff do feel helpless
- Staff member:*
  - Sadly yes
- Staff member:*
  - Resuscitation vs A&E majors – staffing numbers
  - Patients next to each other with very different problems
  - Communication to relative > we are always told to focus on the patient. Relative can feel ignored

The third question (Figure 71) lead staff to thinking beyond the data presented towards the purpose of the event and how the data could be applied. The responses showed that the staff voice in Power Point presentation had not been adequately heard to the same degree as the patient and carer voices in the DVD. This was due to the different media used to present the data; Chapter Four provided the explanation for not filming the staff interviews. However, the recommendation to include staff voices is discussed further in the critical reflection and a second film was made incorporating a re-recorded audio version of their quotes. This second DVD accompanies this thesis. Other comments show staff beginning to question the role of the ED in caring for this patient and carer group, while others highlight emerging suggestions to make changes.

**Figure 71: Staff reaction to film evaluation form: Question 3**

- Is there anything you would like to add to the film or the event today?**
- Staff member:* Very good presentation! Very well done!
- Staff member:* Perhaps for another film, but would be good to include staff voices – see the frustrations they feel delivering palliative care in A&E
- Staff member:*
  - We are working on building new A&E so will have more space and better facilities
  - A&E is not always the best environment for palliative care patients
- Staff member:*
  - How does A&E fit in?
  - Is it about environment or attitude?
- Staff member:* Very useful event and impactful video and discussion

Figures 72 to 74 show the patient, carer and facilitator response to their three questions while watching the film. As this was first time that the patient and carer were seeing their data it was interesting to note their reactions. There was relief at not being alone, but also concern for the staff trying to provide care which again raised questions of the suitability of the ED to provide palliative care. These data were an example of where the lack of representation from patients and carers limited the richness of responses. However, what could be seen is that there were different experiences for people in the ED which needed to be considered when making re-design plans (Figure 72).

**Figure 72: Patient and carer reaction to film evaluation form: Question 1**

<b>Your reactions to watching the film</b>	
<i>Facilitator:</i>	<ul style="list-style-type: none"> <li>○ Distressing, sad to hear about the experiences and how 'poorly' equipped staff in ED to be effectively treating patients with palliative care</li> <li>○ Carers seem to be involved by staff is surprising</li> <li>○ A&amp;E not the best place to treat palliative care</li> </ul>
<i>Carer:</i>	<ul style="list-style-type: none"> <li>○ I had the same experience as these people</li> <li>○ I understand a little more now, we had a whole lot of things the same; I was surprised</li> </ul>
<i>Patient:</i>	<ul style="list-style-type: none"> <li>○ Seeing the film my feeling is that A&amp;E staff are too busy to converse with patients for any length of time because they are too busy</li> </ul>

The comments made to the second question were mixed but positive. The carer's responses, similar to the staff were beginning to look beyond the data shown towards the changes that needed to be made (Figure 73).

**Figure 73: Patient and care reaction to film evaluation form: Question 2**

<b>Does it represent your experience as a patient or carer?</b>	
<i>Carer:</i>	<ul style="list-style-type: none"> <li>○ Yes it does. A lot of frustrating systems in place, but some experiences are bad when bad but good when good, that is the whole story</li> <li>○ Communication is very important to everybody</li> </ul>
<i>Patient:</i>	<ul style="list-style-type: none"> <li>○ Unfortunately I do not know what happened to me in A&amp;E</li> </ul>

**Figure 74: Patient and care reaction to film evaluation form: Question 3**

<b>Is there anything you would like to add to the film or the event today?</b>	
<i>Carer:</i>	<ul style="list-style-type: none"><li>○ Improve environment when people attend</li><li>○ Be more caring towards people who are very ill and dying</li></ul>
<i>Patient:</i>	<ul style="list-style-type: none"><li>○ I am glad that I came</li><li>○ I wish all good things to Rebecca in her efforts</li></ul>

### **7.7.3 Frame 3: First discussion – reactions to the film**

Following the viewing of the film an open discussion took place. Here people were invited and encouraged to feedback what they had felt while watching. This was the first time that the staff, the patient and the carer were able to talk about their experiences. The feedback forms showed that the group were more moved by the negative patient and carer experiences than the positive ones and were starting to question how palliative care could be managed in the ED. This continued in the discussion throughout the remainder of the event.

Notes taken during the event recorded the conversation and how staff responded to some of the questions of the patient and carer. Figure 75 contains an extract from these notes which shows the progression of the discussion exploring the concern of the carer feeling unseen and unheard, and the staff trying to explain the systems and how they were restricted by them in their provision of care.

**Figure 75: Extract from co-design event notes recording the post-film discussion**

<i>Staff member</i> – you realise how important this particular A&E experience is, e.g., someone showing compassion, these experiences really matter. They stay with people. The A&E mind-set is to focus on lifesaving treatments, you can't build relationships over time in the same way that a GP can
<i>Carer</i> – you must feel detached, do your job and then go
<i>Staff member</i> – build up some detachment over time to cope, but we still want to provide the best care at all times, constricted by some of the systems in A&E
<i>Carer</i> – the problem is that you haven't got the time or facilities to deal with people like that. These things affect people's lives forever
<i>Staff member</i> – one person can make such a difference to one person's experience. Impacts on me, makes me really upset to see that compassion wasn't shown. Get one person that doesn't show that, and then that person will remember it forever. We do have the time for one person to go up to someone and ask how they are ...
<i>Carer</i> – sometimes staff are oblivious to them [patients and carers], they don't see you, it's like you're not there, they don't even communicate with you. Bad experience of majors, it was totally different in resuscitation
<i>Staff member</i> – majors and resuscitation – have the same staff working through them, issues of the environment, resuscitation is smaller, more self-contained, higher staff-patient ratio

*Staff member* – majors can be hundreds of patients, ambulance arriving every 5 minutes

*Carer* - it's not the doctors or nurses, it's the system. When is it going to happen that I can get the experience as a human being? So wrapped up in what they're doing, oblivious to everything that's going on around them. Have to look at the whole picture, have to be able to communicate with the older person, e.g., when they say one thing, but actually might mean something else. We think we're going to get better and walk out of there

Through Frame 3 the participant collaborators wrestled with the challenging experiences and implications of the data. Although ED staff were at times defensive, they were willing to be questioned about their processes. For all participants this discussion appeared to be cathartic as evidenced by the comments in the feedback forms, shown throughout this chapter.

#### **7.7.4 Frame 4: Directive discussion**

After lunch the lead facilitator, CD, introduced a directive discussion asking people to start thinking about what needed to be done to address the issues raised in the previous discussion. Figure 76 contains notes made during this process. The extract in Figure 76 emphasises the importance of the patient and carer presence at co-design events. Staff automatically began to discuss different strategies for changing systems and bringing in new processes. Use of the film in training was recommended several times, such use emphasised the need to develop it to include the staff story. Strategies from the US and suggestions made by staff in the feedback sessions were also raised to help provide ideas and stimulate the discussion. However, as the discussion continued the carer interrupted, challenging some of these plans and concerns around cost and time to make changes. She re-emphasised that for the patients and carers what was important was the human element, showing compassion and kindness, things which have no financial cost but are invaluable to those on the receiving end.

#### **Figure 76: Extract from co-design event notes recording the directive discussion**

*Staff member* – film very impactful, is it about the environment or attitude? Can some of this be provided elsewhere, e.g., at home, by a palliative care team, i.e., are they in the right place? Plus whether anything mirroring the mental health services can be provided. IT systems that don't link up is very frustrating. Comment about training, we have done it but maybe it's not systematic enough

*Facilitator* – very high turn over of staff is an issue when it comes to training

*Staff member* – if our nurses saw this video – very powerful. Training issues. Pathway issues. Similar to mental health, we have sickle cell nurse, specialist practitioners. Going to have elderly care cubicles in majors as part of rebuild

*Staff member* – pathway if palliative care patient comes in, where they go, who do we call, especially out of hours, who's coming, if anyone, to see this patient? Can use video during staff training

*Patient* – would it be helpful if everybody wore a bracelet that would give the A&E staff a head start, see a number, wack that number into the system, all the information would be there



*Transformation team member* – COPD patients, advanced care plan, DNR quite clear, but no linkage, they were resuscitated, no IT linkage or sharing of information that has been gathered elsewhere

*Staff member* – yes like when we get someone in from a nursing home with a DNR, but they didn't bring the paperwork

*Facilitator* – a lot of staff talked about having a maternity book for palliative care, gives the patient someone tangible that they have control of, in the same way that COPD patients have their own information, blood gasses etc.

*Staff member* – accessing info out of hours, there's a belief that you can't, that you won't get any help out of hours, even though often you can

*Carer* – I'm looking for the avenue to open, not the door, the avenue is a longer way, have to travel down, journey. A door is just open or closed, and you go into the room. But with an avenue you travel somewhere. So many things to do – it's not just about having enough money. Can pump money in, and it doesn't work, doesn't make all these situations go away. Things to put right are about people. It's so easy, a pat on the back is easy, going up to someone and giving reassurance, doesn't need professional jargon. Just someone to be kind to you – it's human nature

*Facilitator* – participants talked about small but significant changes – how you want the curtain to your cubicle to be, being offered a drink, a phone call. A&E can be isolated, but for the patient and carer it's part of a long process, journey, the small things could ease the way

*Facilitator* - can we teach compassion?

### **7.7.5 Frame 5: Mapping the experience to find the improvement priorities**

Following the directive discussion the lead facilitator, CD, moved the event to the next activity, that of identifying the areas that the collaborators now felt were most important to act upon. This was done by giving everyone two post-it notes and asking them to document their responses to the following questions:

1. What can I or a person in this room do?
2. What big things need to be done by people/groups not in this room?

Once completed the facilitators collected them and analysed them thematically (Tables 21 and 22). This was done in agreement with the collaborators who provided their validation of the themes. Table 21 presents the six themes with the comments made on the post-it notes. These have been colour coded by theme; where comments crossed between themes they have been underlined in the applicable theme colour.

**Table 21: Six themes from the mapping exercise with accompanying collaborator comments**

Theme/Improvement priorities	Comments from post-it notes
<b>Self- management and ownership</b>	<ul style="list-style-type: none"> <li>• Self-management &gt; ownership of records</li> <li>• Palliative care ‘passport’/ID</li> <li>• Give patients more ownership of their records so they can show it as necessary to any care provider</li> <li>• Explore a care book held by patients</li> <li>• <u>Standardised electronic record with advance care plan/“health passport” accessible electronically from the ED</u></li> <li>• <u>Giving each palliative care patient a file with all their information and wishes in it</u></li> </ul>
<b>Pathway/training</b>	<ul style="list-style-type: none"> <li>• Better pathways for palliative care patients. Preferably avoiding them coming to A&amp;E &gt; alternative pathways</li> <li>• Palliative care pathway in A&amp;E</li> <li>• Help create a pathway for patients</li> <li>• Consider patient pathways – extending AOS (acute oncology service) hours v/ED being first port of call</li> <li>• Alternative to A&amp;E – not the best place to receive palliative care</li> <li>• Find a way of helping palliative care patients to avoid A&amp;E altogether</li> <li>• Staff teaching and training: watch video in mandatory training</li> <li>• Think about/find out whether and how ‘compassion’ can be taught and if it’s on the student nurse curriculum</li> <li>• Contact numbers of all palliative care team and when to call who</li> <li>• Update palliative care information in A&amp;E &gt; make it clearer for A&amp;E staff</li> <li>• I will [Staff member]: <ul style="list-style-type: none"> <li>○ Speak to the clinical lead about the training programme and response level</li> <li>○ Speak to CNC (Pan London etc. chronic record for palliative care) about how/try to get over trainers of (<i>unable to read writing – appears to be college centres hospitals</i>)</li> <li>○ Speak to clinical lead about how to advertise what is already available</li> </ul> </li> <li>• ‘I am willing to participate in future meetings/research’ (patient participant)</li> </ul>
<b>Dedicated palliative care space in ED</b>	<ul style="list-style-type: none"> <li>• Dedicated palliative care ‘A&amp;E’ area/service</li> <li>• Dedicated palliative space in A&amp;E</li> <li>• Can we see how to ‘mimic’ model of separate beds for palliative and/or older adults within ED?</li> <li>• Space allocation in ED, if not, what’s alternative?</li> <li>• ‘Outside the room work’ <ul style="list-style-type: none"> <li>○ More responsive palliative care with more staff</li> </ul> </li> </ul>

<b>IT and databases</b>	<ul style="list-style-type: none"> <li>• Integrated systems to enable sharing and tell silo working</li> <li>• <u>Standardised electronic record with advance care plan/“health passport” accessible electronically from the ED</u></li> <li>• Linking various databases</li> <li>• <u>Giving each palliative care patient a file with all their information and wishes in it</u></li> </ul>
<b>Patient experience</b>	<ul style="list-style-type: none"> <li>• A&amp;E made more friendly and advice given to the carer and patient, when attending A&amp;E</li> <li>• Think through how policy can respond to the complexity/time needs of older people in the ED</li> <li>• Personally ensure to acknowledge and involve the carer or relative in future encounters with palliative care patients in the ED</li> <li>• Make connections between different patients’ experiences: get it right for some, get it right for all</li> <li>• I understand how difficult every day is at A&amp;E but at the point we are human beings not just a number, this would make it easier [carer]</li> <li>• Perhaps people could become more dedicated (I am not being adverse) A&amp;E staff are dedicated but be a little more focused [patient]</li> </ul>
<b>Sharing the learning</b>	<ul style="list-style-type: none"> <li>• Show video to frontline staff as part of training</li> <li>• Share the video it is really powerful – with Drs and nurses</li> <li>• Take this video/teaching/learning Trust-wide, as for ‘Barbara’s story’ (through nursing directorate)</li> </ul>

### 7.7.6 Frame 6: Identifying the shared improvement priorities

Once the post-it notes had been mapped out and arranged thematically with the agreement and validation of the collaborators, the improvement priorities were identified. Frame 6 now moves the narrative through a discussion of the themes, and how they represented shared improvement priorities that built on the original improvement priorities selected by staff, patients and carers (Table 22).

**Table 22: Visual representation of the relationship between the original and shared improvement priorities**

Staff priorities	Patient/carers priorities	Shared priorities
Helping patients and carers find their way	Finding our way	Pathways/training
Being informed and informing patients and carers	Knowing what's happening	Self-management and ownership AND IT and databases
Seeing the person in the patient	Seeing the person in the patient	Patient experience AND Dedicated palliative care space in ED
Expectations of the care we can provide	Expectations of care	Sharing the learning

#### *Improvement priority - Pathways/training:*

This theme related closely to the staff improvement priority 'Helping patients and carers find their way' and the patient-carer improvement priority 'Finding our way'. ED staff work with algorithms, systems and pathways to help manage the vast range of conditions that people attend the ED with. The response of the collaborators while exploring how to improve the experiences of patients and carers trying to navigate their way through the ED was to improve on existing pathways and develop new ones is shown in Table 21.

#### *Improvement priorities 2 and 3 – Self-management and ownership AND I.T. and databases:*

Responding to the improvement priorities 'Being informed and informing patients and carers' and 'Knowing what's happening' the collaborators looked for ways that patients and carers would be better informed about the ED processes and their treatment while in the ED. There was agreement that patients could be better informed and equipped with their own data prior to entering the ED, as shown in Table 21, for example carrying information about their care and wishes. From the perspective of the ED staff, access to information to know what had happened, who to contact and what was going on, were discussed as key factors that helped

or hindered a patient visit. Table 21 showed how the collaborators reflected that shared access to databases would help reduce silo working environments and support the ED staff to quickly and efficiently access vital patient information.

*Improvement priorities 4 and 5 – Patient experience AND Dedicated palliative care space in the ED:*

‘Seeing the person in the patient’ was the improvement priority that received most discussion. The activities outlined in Frame 5 had provided a space for ED-based staff to discuss their concerns. They had looked at the systems from the perspective of patients and carers, rather than focusing on time and targets. Similar to the work in the US at Mount Sinai discussed in Chapter Five, the suggestions for improvements were practical and personal. Practical solutions involved allocation of targeted space just for palliative care patients, while personal solutions explored involving patients and carers more closely in decisions about their care, and reminders for staff to provide more information and advice in a kindly manner.

*Improvement priority 6 – Sharing the learning:*

Collaborators at the co-design event recognised the differences in expectations of staff, patients and carers about an ED experience. The staff collaborators were impacted by the patient-carer film and how it highlighted that some very basic needs of patients and carers that were often being missed. These included simple acts like giving choice in how the curtain to the ED cubicle was left, offering a drink to patients, or showing compassion through small gestures like a gentle hand on the shoulder and a smile.

‘Sharing the learning’ referred to passing on the learning that had emerged through the research of this thesis, and specifically using the patient-carer film as a training tool. The rationale was that by making staff aware of the things that patients and carers were actually concerned about, staff would be better equipped to tailor their care. This would help to reduce staff concerns that patients and carers harboured significant expectations that they simply cannot meet in the current ED model.

### **7.7.7 Frame 7: Identifying ‘next steps’**

Aim 2 of the co-design event was the ‘collaborative working to decide the “next steps” in the redesign and implementation process.’ The improvement priorities and the data from the post-it notes were used as guidance for identifying how to move the discussion into the practicalities of starting to make improvements and changes to practice. This was a simple

process whereby the lead facilitator, CD, asked those present what they felt they could do, and what they were willing to do. Figure 66 shows how the collaborators' responses were written on a flip chart. Following the co-design event the list was documented and e-mailed to all those present, as well as collaborators who had not been able to attend (Table 23); this included patients and carers, as well as the clinical lead at the ED. The event concluded with the agreement that follow up would occur in several months to determine the progression of the next steps. It was agreed that all the collaborators and participants would be informed of the progress as the changes occurred.

**Table 23: Co-design event actions list**

Who	Action
ED nurse	Arrange for the film to be incorporated into mandatory training
ED nurse and palliative care consultant	Help create a pathway for palliative care patients in A&E
Transformation team	Link with ED nurse and palliative care consultant on pathway work
Transformation team	When A&E patient passport work is launched, involve palliative care in this project
ED Matron	Link the findings of this film to the work in developing elderly care 'cubicles' within the new design for the A&E department
Palliative care consultant & GP trainee/ED registrar	Raise the awareness amongst staff of the palliative care services and support available
GP trainee/ED registrar	Look at the way in which other hospitals link up their IT systems to ensure information about patients is available to clinicians
Transformation team	Spread the message about the power of patient videos in GSTT
CD & palliative care consultant	Take the film and key findings to the Trust's End of Life Care group
CD	Take the film and key findings to the Trust's Acute Oncology Service team
RB	Work with Marie Curie to disseminate findings
RB	Share knowledge about patient experience insights internationally with Mount Sinai, New York, USA

## 7.8 Critical reflection

In this section the narrative turns to reflect on my role in the co-design event. Following the chronological narrative within the chapter I move from the preparing and running of the event, managing unexpected and challenging factors such as the fire evacuation and strong personalities in the group, to the selection of the improvement priorities and next steps. My own feelings and their influence on my ability to carry the event are reflected upon in regards

to nerves, pressure, concerns about reactions to the staff, patient and carer data. Woven into this critical reflection are the event evaluation data gathered from the attendees.

### **Organisation of the event**

As with many of the activities required in conducting this EBCD study, this was the first time I had ever had to plan and run an event. The EBCD Toolkit on the King's Fund website (The King's Fund, 2013a) was a useful aid, and I was able to refer to experienced EBCD researchers for advice. CD was especially helpful and it was she who recommended that a mapping exercise be included. I had not thought this would be possible given the limited time frame but it was an element that proved vital to meeting the aims of the co-design event. Regardless of my lack of experience in running an event, the limited time frame was an added pressure and juggling the co-design event planning while concluding the patient-carer analysis and film making was challenging, but did provide focus.

The facilitator support was an important element before the event as well as during it. As CD led the event, BG took notes and KL helped with the mapping exercise, I was able to be part of the discussion, acting as a participant with knowledge of both sides of the ED experience. Undertaking the event in my capacity as a lone researcher would not have been feasible or successful, which demonstrates the importance of collaboration in an EBCD project.

In the event evaluation the collaborators were asked for their opinion on the preparation and administration of the event. Given the challenges leading up to it, the responses to the event evaluation form asking for the participants' overall impressions were encouraging, with 100% selecting excellent/good. To determine data that could be fed into future events they were also asked the following question 'What could be improved if this event were to be run again?' Figure 77 contains the responses of participants.

**Figure 77: Participants responses: 'What could be improved if this event were run again?'**

- Nothing
- Invite community nursing, palliative care team @home
- Enhanced rapid response
- Nothing
- Really good event – seemed to cover it all!
- Can't fault it – perhaps more key people to be in the room @home team in the community
- Nothing

- No fire alarm ☺
- More time? Felt – maybe – there could have been more time for discussion e.g. whole event over 3-4 hours

An interesting response was the suggested invitation to the co-design event of community based teams. These groups are often key in the success or failure of discharges from hospital and preventing admissions. At the co-design event they would be able to offer support to the ED and improve discharge home from the ED rather than admission. Prior to the event inviting representatives from community groups had actually been discussed, but as this was the first time the film was being shown to the ED staff it was considered better to include staff external to the ED to later meetings. Reflecting on the speed that the participants began to highlight areas that could be improved, this may not have been necessary. In future research the inclusion of other services is something to consider.

The final comment referencing the time limitation was a valid point that has been discussed. However, in order to facilitate collaborative working with this particular patient and carer group this was an important decision and one I do not regret.

### **Meeting other people and talking about experiences**

One of the major challenges at the event was the lack of representation from people who were familiar with the project. I do feel this was a limitation and if it were possible I would have run it at a later date when the clinical lead and a senior nurse familiar with the project would have been able to attend. It was not only the lack of familiarity that was a concern. I was also aware of the lack of existing relationships between the majority of the collaborators, a point that has been raised throughout the chapter, as trust and good relationships are vital to the success of collaborative endeavours.

An example of these challenges was in the attendance of the matron. It was helpful to have him present due to his seniority which meant that he could agree to the plans being made, and feedback findings to the management within the department. However, his lack of familiarity with the study was a challenge in the discussion as he was quite defensive with some of comments of the film in the early stages, whereas the clinical lead and PDN were aware of this feedback through previous discussions. Despite this, where certain concerns were raised he was able to provide professional insight. One example concerned very ill patients who tend to be quieter and potentially overlooked when compared with people who come to the ED for alcohol or drug related issues, who are often much louder and are therefore seen to get



more attention. He highlighted the role of the ED in caring for everyone's needs, reminding the room that there was no hierarchy for who is more deserving of care. This particular discussion became quite fruitful and led to the improvement priority of identifying space for older and terminally ill patients in the ED; something that was already part of the ED transformation plans. I was then able to provide the matron with the design principles from the fieldtrip discussed in Chapter Five. His response and use of this information is presented in Chapter Eight.

Despite my concerns, the response from the participants to this aspect of the event was encouraging and reflected that those present had found it a useful process. Eight participants said that meeting other patients, carers and staff to talk about their experiences had been excellent and two said it was good. The statements provided shown in the comments box also reflected this as exemplified in the following quotes, while also highlighting that the small numbers were noted and recognised as a limitation:

*'These experiences are best recounted/told straight from the patient – video in person.'*

*'It was a really good meeting. It would have been good to have a few more patients/carers present – although it might not have made any difference to outcome.'*

*'Makes it very real and brings back the reality of human touch or the lack of human touch.'*

### **Reactions and experiences of watching the film and seeing the staff presentation**

I was very nervous while sharing back the staff data and during the viewing of the film, as some of the content reported on negative experiences and I knew it would be challenging for the staff participants to hear.

In the evaluation form, the participants were asked two questions about this part of the event. First, if it was a good representation of what it was like to be a patient, carer or staff member at St Thomas' ED, and second what their experience of viewing the data was like. Seven participants said it was an excellent representation of their experiences and one said it was average. Nine people said the experience of viewing the data was excellent, and one person said it was good. Figure 78 provides the comments made in response to the first question, and Figure 79 to the second. The reactions were affirming and demonstrated that, despite certain challenges, the staff and patient story were predominantly recognised by those working in the same environment.

**Figure 78: Participant evaluation on how good the representation of staff, patient and carer experience was**

- Emphasis was on patient's and carers experiences which was correct to have mixture of experiences, good and bad, shared
- Very powerful film
- Sometimes, it depends on which staff are working that day with that patient: because some experiences great and some negative
- Very real experiences from patients and carers
- Highlights how poor/ill equipped A&E is in dealing with palliative patients and carers
- Difficult to know – hopefully not
- Very interesting
- Staff presentation was excellent. Care
- I'm not sure as don't work in A&E and haven't attended. My instinct says that is a good representation. Might benefit of a few more participants in terms of staff saying is this representative

**Figure 79: Participant comments on their experiences of watching the film**

- Very impactful film, difficult to watch at times but giving an insight into patient experience we would otherwise not know
- Powerful/a call to action!
- Cannot fail to be moved by it
- Really thought about things that I can change myself and influence and the small things that are important
- Very emotive film – really hit home how important basic care and patient information is!
- Some people's experiences were very sad
- I am sure things might change for the better
- Powerful. Emotive. Well Edited. Good length. Would have been good to have videos of staff mixed in to show the mirroring you talked about at the beginning

The final comment in Figure 79 raised a previously mentioned point about the voice and representation of staff data. The power point presentation and written quotes could not compare in impact to the film, which was an emotive and vulnerable presentation from real people. The improvement priorities included several requests to use the film for training and development in the ED but also potentially throughout GSTT. It was agreed that I would make a second version of the DVD which included the staff story and their improvement priorities, voiced over by actors. Permission had not been granted during Stage 2 to use the audio recordings of staff data in this way and many staff had moved on from the ED.

However, there was ethical approval and consent from the participants to use the staff data in dissemination activities, which is what the DVD was now to become.

During the event I was questioned about why I had not filmed the interviews with staff. This was a conscious decision made to protect the identity and safety of the ED staff. While patients and carers were talking only of their own experiences which they controlled the rights to, staff were reporting on multiple patient and carer accounts, as well as their own experiences. ED staff are often at risk from the public due to the front line nature of their work and the distressing situations about which they have to make life or death decisions. For this reason the second version of the DVD, which accompanies this thesis, contains only the audio recordings of quotes voiced by actors.

N.B. Please watch the staff sections of the DVD that accompanies this thesis at this stage.

### **Discussion groups**

Starting the event with a fire alarm and building evacuation increasing my nerves and I was desperately worried I would have to cancel the event and re-organise it. Although it would have been possible I was concerned for everyone who had made the effort to attend. Ultimately the fire alarm actually served to help conversation and ease tension, but I was aware of the time pressure increasing as a result. Despite the time pressure and false start, the two discussion sections seemed to go well thanks to the excellent facilitation of CD and the interest in the topic of those present.

The participants were respectful of each other's opinions, even when there was some disagreement or differences in opinions, such as outlined previously. I felt that the discussion moved incredibly quickly but smoothly through to the 'next steps' stage and it appeared that everyone had been able to share their opinions. The event evaluation asked participants if they felt that the discussion served as a useful way to reflect on their experiences and identify improvement priorities within the ED. Five people said this section was excellent and three rated it good. The written comments were equally as positive, particularly in regards to having the space to hear everyone's point of view as shown in the selected quotes below:

*'I thought the discussion was good and well facilitated, particularly given the limited time!'*

*'Good to have members of staff/trust attending who can take this project forward and make a difference.'*

### Selecting improvement priorities

In many ways the rapid progression of the event was the greatest success of this study. A group of people who were largely unfamiliar with the study and each other quickly united and worked collaboratively to produce a clear plan for making improvements in the provision of palliative care in the ED. Participants were asked in the evaluation form if they felt that the final improvement priorities reflected their experiences of what needed to be improved, to which all responded positively.

### My changing role

A personal measure of success for the event was how my role had changed. Leading up to the co-design event I was the sole researcher; the protagonist who had driven this story from its outset. The study had been interrupted for three months prior to Stage 3 of the EBCD process and nothing had happened during this time to progress the research until I returned and could continue pushing it forward. At the start of the event I was the representative for the voice of the staff, patients and carers, and it was I who had drawn the group together. However, once the data had been shared my role visibly altered; the facilitation meant I was able to participate in discussions as stated, but I actually said very little. The data spoke for itself and those present at the event responded to the needs being expressed passionately and with interest.

In the final stages of the mapping event when the lead facilitator, CD, asked the collaborators what they were willing to do in response to the improvement priorities selected, everyone present offered their time and skills, with different staff members agreeing to work together. It was at this stage that my role changed from lead researcher to observer and supporter, and my post-event activities were supportive rather than directive.

I have at times questioned the validity of terming this study an EBCD project, based on the limited collaboration prior to the co-design event. However, the event and its outcomes epitomised all that an EBCD project should be. To refer once again to the quote given at the start of this chapter, ‘...the direct and active participation of staff and patient...produces implementation and action...’ (Tsianakas et al., 2012, p.2645).

Participants were asked at the conclusion of the evaluation form if they had any further comments. Figure 80 contains the three remarks given which were both reassuring and helpful as I moved away from the practicalities of conducting the thesis and into the final stages of monitoring the impact.

**Figure 80: Final comments on the event from participants**

Very good presentation – so glad I attended! Excellent!! Good luck I am so glad a person who put it together was so wonderful
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## **7.9 Conclusion**

From the co-design event there were six clear areas in which the participants had collaboratively agreed plans for improvements to better the experiences of palliative care for older people, their carers and staff in the ED. Roles and tasks had been identified and all that remained was to feedback these outcomes to those who had been unable to attend. The final chapter of the story of the research was to return to the ED to identify what, if any changes had been made in the months following the event. In Chapter Eight the narrative explores and critically reflects on the influence of these individual and shared stories told from Chapters Four to Seven, as well as considering the unexpected developments and opportunities that emerged along the way.

## **CHAPTER EIGHT: THE INFLUENCE AND CONSEQUENCES OF THE STORY**

### **8.1 Introduction**

The purpose of this chapter is to reflect upon the influence and consequences of each stage of the EBCD study, following the threads to four months post co-design event. Within this chapter the conduct and findings of the research are considered in regards to their implications for future EBCD research; the patients and carers who participated in the research; staff working at St Thomas' ED; the palliative care delivery provided by St Thomas' ED; wider palliative and emergency clinical practice; and policy relating to palliative care in the ED.

This study aimed to improve experiences of palliative care in the ED for older people, their carers and staff. However, increasingly throughout this endeavour the narrative demonstrated the sizable challenge of the aim in both the infancy and paucity of literature in this field, and the extent of foundational exploratory work required for the study itself. Therefore, while the aim remained the same, it became clear that meeting it in full was beyond the capacity of a single study. Instead, the story of this research serves to act as a contributing chapter to a much wider story requiring input from many additional levels including community and inpatient services, policy makers and the patients and carers themselves.

The time and capacity limitations prevented a full EBCD project from being undertaken, meaning that it would be inappropriate to make claims of interventions or impact, or to attempt to measure the outcomes of this study in such a way. In addition, staff turnover at the research site meant that the staff members involved in the research at the conclusion of the study were not the same as those present at its start. This prevented evaluation of personal impact and exploration of the experience of being involved in the study. Despite this, the very undertaking of this research exerted an influence that led to changes in different aspects of palliative care delivery at St Thomas' ED.

One of the main challenges for this thesis has been maintaining the three intertwined threads of the study topic within its research paradigm, whilst allowing it to adapt to the changing social and political developments that occurred during its undertaking. The relationship that has developed between palliative care, older people and their carers, and the ED and ED staff,

has been well documented within this thesis. This relationship is at the very core of the dichotomy. Beyond the innermost point where these three threads meet, they also interact in dual relationships (palliative care in the ED, older people in the ED, palliative care and older people). Yet all three threads also stand alone, each with their own agendas and challenges.

Encompassing the research topic and the three threads is the research paradigm I used to understand these relationships, and to explore the experiences that occur for the patients, carers and staff when they become entwined. The methodology that held this study in place was EBCD, which sits within an interpretive-constructivist ontology and epistemology. These allowed the research to be driven forward to derive meaning and understanding from these interwoven threads.

Finally are the external changes in policy and practice that impacted upon the management of this thesis within its theoretical paradigm. These were first discussed in Chapter One and are to be concluded in this chapter. The national removal of the LCP (Williams, 2013) and the political and media focus on ED performance (Blunt et al., 2015) based on time-orientated targets were unanticipated. Their occurrence in the latter half of the study meant that my developing understanding of where and how this research sat within national policies and practice was discomposed. By reflecting on the impact of these external developments on the conduct of the research within its theoretical underpinning I have been able to identify positive outcomes as well as challenges that stemmed from these developments.

The narrative now moves between each of these different threads and circles in turn, considering the influence and consequences of the study for each. First to be considered are the patients and carers.

## **8.2 Influence and consequences of the study for the patients and carers**

The previous section highlighted that the patient and carer experience had been largely unknown and elusive to capture throughout the study process. The literature was sparse and the fieldtrip to Mount Sinai had only emphasised how challenging it would be engage patients and carers in this study through the ED. However, once the interview process was underway and the narratives began to unfold they provided an unexpected sense of completion to the story of this research. In reflecting on the influence and consequences of the study for this participant group, it is difficult to gauge the full impact that participating

may have had on them due to the limited time they could provide to the research. Ending the study before Stages 5 (on-going co-design work in small groups) and 6 (celebration and review event) of the EBCD process meant that the patients and carers reflections could not be recorded, or their input celebrated. In contrast, the following sections demonstrate that the influence and consequences of their participation for the staff group and service delivery at St Thomas' ED was more visible.

Across the majority of the interviews, patients and carers stated that they found the process therapeutic. For those who had had negative experiences in the ED, being able to reflect and share their concerns was helpful. There was a mixture of feeling that care wouldn't change and hope that their stories might make a difference. Where patients and carers had had positive experiences they seemed pleased to be able to share this and say thank you. Chapter Six discussed two particularly distressing incidences where participants became very upset, and one where the participant had died and the bereaved spouse had expressed their concerns about the ED care. In all three of these incidences, although there was ongoing grief and bereavement for the loss of a loved one, being given the space to reflect, being heard and having their concerns follow up seemed to be particularly cathartic.

In the forward to the Oxford Textbook of Palliative Medicine, Derek Doyle offers an insightful comment about the effect of palliative care:

*'Palliative medicine...says to the lonely "you are not alone". It says to the fearful "we are near you and understand"...it says what everyone in the world at some time or other wants to hear "you matter because you are you".'* (Doyle, 2010, p.xxiv)

In stark contrast, during the ED staff interviews, one senior nurse said:

*'...because you have to make life and death decisions then the niceties go out the window...'*

ED senior staff nurse

Juxtaposing these quotes initially suggested a paradox whereby palliative care cannot be provided in the ED. However, the simplicity of the needs highlighted by patients and carers began to suggest that the aim of this thesis could be met through palliative care being delivered in the busy ED in gentle, quick and unassuming ways. Although the co-design event, discussed further later in this chapter, had a greater influence on practice in drawing out a shared story, for this study Stage 3 'gathering the patient and carer stories' was a key point for the patients and carers.



One of the challenges that has been discussed at length in this thesis are the inherent difficulties in engaging and maintaining input and collaboration with older palliative care patients and their carers. Only one patient and one carer of the already small sample in this study were able to attend the co-design event. Their feedback on the day as presented in the previous chapter shows that they valued and appreciated being involved in the EBCD process. Informal verbal communication with the remaining patient and carer participants indicated that the majority shared this perspective. However, there is regrettably insufficient data available to explore and discuss the full influence and consequences of the study for the patients and carers.

### **8.3 Influence and consequences of the study for the ED staff**

Moving the narrative on from the patients and carers to the ED staff, the influence and consequences of the study are more visible. In Stage 2 of the EBCD process the staff stories demonstrated anxiety and uncertainty about what palliative patients needed and how to provide the best care. Stage 3 demonstrated that the experiences of the patients and carers mirrored those of staff while providing additional context and information about external factors leading to admissions. The stories from the patients and carers revealed surprisingly simple needs, given the complexity of conditions and terminal stage for many of them. The data gathered from the patients and carers was used by the clinical lead to encourage staff to start considering the small but significant things that make a difference to patients, carers and staff alike. The following quote is taken from an e-mail exchange with the palliative care link nurse for the ED who had been involved in the study, offering feedback on the co-design event:

*‘...As Palliative Care link nurse at the time, I wasn’t quite sure how to improve palliative care in the A&E. After going to the presentation of the study and specifically watching the video of palliative care patients’ and families experiences of being in the A&E, I suddenly saw what impact small changes could have on improving their basic care. I also realised how much could be done to improve their overall experience during their time in the A&E. Things such as touching the person, acknowledging their presence while walking past, offering something to drink or to eat while they wait or offering them a phone call are all basic nursing skills which*

*A&E nurses can easily forget as they rush around doing what may seem as more important clinical activities in the acute setting...'*

E-mail extract from the ED Palliative Care Link Nurse

The interview phase of Stage 2 was in many ways a gentle introduction to the study for the ED staff as it required no further effort other than to discuss personal experiences and opinions. The attitude from staff during interviews was one of interest in the topic, or willingness to participate simply to support a fellow clinician undertaking research. The demand on their time was relatively small. Despite this relatively passive role, during many of the interviews there was an observed change in attitude and perspective on palliative care and related issues as shown in the interview extract below:

*'...maybe we have to change the perspective about what the doctors think their role is here, because from having this conversation there is probably a lot of people that could go to palliative care...after this, after this interview I'll probably be thinking more about palliative care, I think...'*

(ED staff nurse, Interview 7)

As the study progressed through Stage 2 it necessitated greater involvement from a wider spectrum of the staff in the ED to review and approve the findings and analysis from the interviews. The input required from staff was more active at this stage, and the influence of this activity was seen to be on the mind-set and perspectives towards their own experiences of palliative care. Providing staff with the quotes and an interpretation of their experiences evoked both discussion and reflection. Although some staff chose not to participate, the response from the majority who did, suggested that what was being shown resonated. The staff may not have been leading the work at this stage, but their control over the findings and how they were presented was shown to be understood by approving the interpretation of their experiences.

These early feedback sessions and emphasis on staff ownership for the direction of their data in the study was an important part of introducing staff to the concept of being change agents. The latter part of the sessions focused on selecting improvement priorities. As staff engaged in this activity they took up the role of change agent quickly in each session, suggesting immediate and long term improvements which they would value. These improvement ideas were fed back to the ED management and palliative care team. This was the first stage where the study was seen to exert a practical influence.

A significant change that emerged from Stage 2 and had direct consequences for the ED staff was the collation and dissemination of palliative care services and support information. Part of the remit and permission to undertake the feedback sessions had been based on the agreement that they would also include some teaching in palliative care. The interview findings had shown that staff seemed to have little knowledge about the wealth of palliative care services and support available to them at St Thomas' Hospital. Therefore the palliative care team were consulted as part of the preparation for the feedback session and a short document was developed containing an outline of the services, contact numbers, hours of operation and list of useful resources. This document was well received and put into use in the main department and on the shared computer desktop. After the co-design event the document was updated by staff and moved to a different folder on the desktop which contained similar information for different services.

Stage 2 of the EBCD process was an exploratory one that sought to determine the main concerns for an area of practice for staff, and to select those that were of the highest priority for improvement. However, as this reflection has shown, the very act of undertaking the stage triggered a response in the participating staff, who instinctively offered practical ideas and solutions. The same response was found in the supportive management and palliative care teams, who listened to the concerns and feedback of staff and reacted promptly by developing and implementing changes where they could.

At the end of 2013 following the end of Stage 2 the report on the LCP was published, officially removing the Pathway from practice (Williams, 2013). The removal of the LCP shook the staff working at St Thomas' ED. For many it had been the only framework they were aware of that provided clear guidance of end of life care. The experiential staff data originally collected frequently referenced the LCP, either in a discussion of how it helped them provide care, or as shorthand for understanding the prognosis of palliative care patients. This shorthand terminology was one of the criticisms of the official review, as it could confuse patients and carers and be misleading (Williams, 2013). Informal interviews and discussion conducted in the ED during teaching sessions and recruitment for Stage 3 of the EBCD process revealed that staff experiences still varied, and that many were increasingly uncertain of their role in the delivery of palliative and end of life care.

As the study progressed there were positive outcomes from palliative care developments for this research. The early months of setting up the study and collecting data had been

challenging because of the taboo of discussing death and dying, particularly in the ED. This changed with the removal of the LCP, and being present in the ED during this seminal change in palliative care delivery in the UK was fortuitous for the progression of the study and the developments in the ED. The exploratory nature of this thesis into understanding and improving palliative care, based on the lived experiences of those within it, encapsulated the changing zeitgeist. Rather than simply participating in the research, the uncertainty around palliative care delivery led ED staff to open a dialogue. Staff requested information, asked questions and discussed patient cases all of which influenced the care provided at St Thomas' ED.

#### **8.4 Influence and consequences of the study for St Thomas' ED**

From the first stage of their involvement in this study through to the end, the staff at St Thomas' ED drove forward changes and improvements in care delivery. The following extract is taken from a palliative care consultant four months after the study concluded, reflecting on the changes that had occurred at the study site due to the research processes:

*'...Your involvement has certainly facilitated more of a dialogue. The workshop in particular put us in contact with two very able, enthusiastic members of the team who were keen to work with us and make access to palliative care easier to understand for the emergency department staff. With their help we revised the information on palliative care services and put it on the desktop which they use. The walk-throughs which started in May 2014 have meant that I know some of the staff and their faces and hopefully have improved access. The teaching sessions in which we jointly participated in March/April 2014 gave us an opportunity to speak to the team about what palliative care does in a way that was easier for them to assimilate and also meant that they know our faces and gave us some useful ideas about how to work more easily with them. My sense is that there are more referrals directly to us from the ED... There are issues which still remain - principally the issue of how to flag palliative care patients when they attend ED. The complexity of IT systems has made this difficult to solve - but we will keep working on this...'*

E-mail extract from a Palliative Care Consultant

The following section leads the narrative through these changes and developments, reflecting on the influence of this research at St Thomas' ED. There were two main changes that

happened as a direct result of Stage 2 including collation and dissemination of palliative care services and support information which was discussed in the previous section.

The first major change was the redesigning of the Electronic Patient Records (EPR) referral form. During interviews staff expressed a lack of awareness of palliative care support within Guy's and St Thomas' NHS Foundation Trust. This included little to no knowledge of a direct referral form for patients with medical or social needs. The EPR form had been in existence for approximately one year prior to the start of the study in 2011 but had never been used. The staff response was fed back, to the surprise of the palliative care team who had thought the form was not being used due to lack of need. In response the form was rewritten and restructured collaboratively by staff from the ED and palliative care team and reissued into practice where it was subsequently used.

The second major change was initiated during the feedback sessions when ED staff commented on different specialty teams who would visit the ED and perform 'walk-throughs'. These consisted of walking through the department, asking staff if any patients who needed their input had been admitted, or if staff had any concerns or questions about their patient group. This was reported as being helpful, reducing the isolation of the ED and improving organisational relationships. A number of ED staff had cited problems accessing the palliative care team, and most were unaware that there was a palliative care team based at the St Thomas' Westminster site where the ED is. Many thought that the only one was at the Guy's London Bridge site. Again, when fed back to the palliative care team this was received with interest. The team then initiated ED walk-throughs three times a week by one of the palliative care consultants. An extract from an e-mail communication from the palliative care team feeding back on these changes suggested that they were positively received and that further developments were planned:

*'...Walk-throughs are developing. Beginning to see the same faces again and had some interesting conversations as well as 2 referrals via Hospital Outpatient Treatment (HOT) clinic referral...Often just missing people because of the time we attend but I can see the value of going at that time, and reminding them of what we do for the day ahead. Am keeping a log of contacts made. Our presence has coincided with the hospital at home team raising their profile, so there is some natural linkage. Also the COPD team work is developing so that will probably also overlap...'*

E-mail extract from the Palliative Care Team

Further improvements in the provision of palliative care within St Thomas' ED have been made in the four months following the co-design event as a direct result of viewing and discussing the patient, carer and staff stories. The following information includes feedback from various participants at the co-design event who volunteered to investigate and instigate change.

Earlier chapters have discussed examples of silo-working, whereby the palliative care team and the ED rarely connected. As the study progressed the palliative care team became more involved in the ED such as in teaching and the walk-throughs previously mentioned. Following the co-design event the attending palliative care consultant had agreed to meet with the ED nurse and registrar to work on improving palliative care processes and information sharing between the palliative care team and ED. The following extract is taken with permission from an e-mail exchange between these practitioners which reveals how little had been known about the other's needs (Figure 81). Positively it also indicates a developing relationship between core staff members in palliative and emergency medicine born out of the work of this research. The e-mail exchange suggests that the outcomes of this collaboration are still emerging but that there is commitment from both sides to improve the palliative care delivery at St Thomas' ED. There seems to be a growing recognition in the ED of what the lead consultant calls 'soft skills', the small but significant interactions that are so greatly valued by patients and carers as expressed in their film and at the co-design event.

**Figure 81 : E-mail communication between the palliative care team and ED following the co-design event**

***From the palliative care consultant:***

I have just come from an interesting meeting based on Rebecca Blackwell's research. She showed a very powerful film about patients' and carers' experiences.

I just wanted to say that as a result of this two people who were there from ED - the end of life link nurse and GP trainee/registrar [*present at the co-design event\**] wanted to volunteer to look at processes within ED relating to palliative care. I hope this is OK with you. We hope to meet in the next 2-3 weeks and will obviously feedback any recommendations to you. We discussed developing a palliative care referral system which everyone is more aware of and making contact numbers more visible. It has come up during discussions with people since we made the HOT clinic referral live that the form is probably not fit for purpose and needs revision.

From our own team I have been asked to contact you about:

**1. Response times from palliative care**

- as you probably know we are quite a small service and cannot undertake to do face to face consultations within 30 minutes. However we provide a 24 hours on call service which is covered by consultants (not all from this trust, registrars at weekends (again not all from this trust) and our community nurses are also on call 24/7. We can therefore always provide a telephone response within 30 minutes.

- on weekdays in office hours we would also aim to provide a face to face consultation, although again attending in ED within 30 minutes would provide a considerable challenge which our current resources would not allow on all occasions .

## **2. Teaching for ED**

It would be helpful to know what teaching you would like to the ED on a regular basis.

We have provided teaching to all nursing staff earlier this year I believe and have also done a couple of sessions with the registrars/junior doctors. All F1s are getting a teaching sessions as are F2s

How frequently would you like this repeated?

Is there additional teaching you would like?

We have been working on a strategy for teaching and have available

-a 10 minute DVD that is on the palliative care website which covers all the tools we use and outlines the role of palliative care

- Sage and Thyme - a 3 hour basic communication skills programme

- Transformers - a 2 day programme which covers end of life care in a little more detail, including priorities of care for the dying and the AMBER care bundle

- new this year we are developing a simulation 1 day programme covering discussing difficult issues such as DNACPR and advanced care planning for consultants and senior StRs

-eLearning module on AMBER care bundle

We can try to deliver bespoke training for ED if you have other ideas about what is needed related to our speciality.

## **REPLY**

### ***From the ED lead consultant:***

Thanks for this – I was sorry not to be able to go. Obviously knew GP trainee/ED registrar was going so of course fine for her to look at processes. I am hoping to get Rebecca to present some of her work to the ED at one of our departmental meetings. She has talked through some of her results and there is some very, very important stuff for us – not just for palliative care patients but important for all patients.

We get the response time issue. In many ways things are too late once the patient has got in. My ideal world would be that patients never come in saying they did not know who to call for help when they are already involved in oncology or heart failure etc. It seems still quite often that patients do not have a good understanding of who they can call on for support and we still have inappropriate LAS

[London Ambulance Service\*\*] cardiac arrest transfers when perhaps a community DNAR [Do Not Attempt Resuscitation\*\*] and a plan would have been better

Teaching – I will link you to our teaching lead who is back from leave next week re teaching as I am sure would be useful. We need to improve our soft skills perhaps more than our clinical interventions!

## **UPDATE**

### ***From the palliative care consultant:***

The ED registrar/trainee GP, palliative care link nurse and I met after Rebecca Blackwell's workshop.

The ED registrar/trainee GP very kindly reformatted the information on how to refer to Palliative care to make it more accessible to ED staff. This now seems much clearer to all of us. If you agree could you replace the Palliative care information under clinical guidelines on your desktop with this version?

We are currently working on a couple of other issues which may make information already available clearer.

**\*names have been removed where permission had not been obtained to include identifiable information.**

**\*\*information has been added for clarity within this thesis.**

The palliative care link nurse and trainee GP/ED registrar who were present at the co-design event both volunteered to explore and improve the pathway through the ED experienced by palliative care patients and their carers. The palliative care link nurse was keen to implement the patient and carer film into staff training. Trainee GP/ED registrar volunteered to focus on raising awareness of the palliative care services available at Guys and St Thomas' NHS Foundation Trust amongst ED staff as well as exploring ways to improve IT systems affecting the transfer of patient information. The e-mail extracts below were provided by the palliative care link nurse and trainee GP/ED registrar who gave feedback on the changes and progress made following the co-design event.

In addition to the practical changes listed by these ED practitioners, their extracts also demonstrate their ownership of the research data and findings. As neither of these members of staff had been involved in this study prior to the co-design event, it is interesting to see how effective the stories shared through the patient and carer film and subsequent discussion were in engaging people who were new to the study at this latter stage.

*'...This knowledge prompted us to consider placing the sick palliative care patient away from other patient groups, especially the noisy or disruptive patients and educating A&E staff on what really matters to this patient group and their family members.*

*It prompted us to create an easily available flowchart of all resources available and in what circumstances they should/could be contacted.*

*We are also starting a trial in triage where sicker or special needs patients are streamed past triage and directly into the department and palliative care patients will be specifically included in this group in order to reduce time spent in the waiting area and therefore the A&E as a whole.*

*We also had a meeting with the palliative care consultant in order to try to connect the information on her department's patients with information that could also be accessed on the A&E database. We also discussed the idea of creating files for palliative care patients to bring with them to the A&E so that their care plans and details are immediately available to staff on arrival in the A&E.*

*The research has also encouraged discussion and an awareness of the special needs of palliative care patients and their family members and what training should be*



*offered to A&E staff and has clearly had a great impact on me and the department as a whole!...*

E-mail extract from the Palliative Care Link Nurse

*'...I really enjoyed and felt very positive about being involved in the co-design event and subsequent work to aim to improve the experience of Palliative Care patients in the ED. From the event for me personally, the importance of the carer or relative was greatly emphasised and I tried to remember to think of their experience and involve them more from that day forwards. More widely, it was good to hear the other attendees talking about an effort to link up care documentation for access over several different hospital trusts.*

*After the event I was able to meet with the palliative care link nurse and palliative care consultant where we talked through a lot of practical issues around boundaries to providing best care for patients in the ED from a 'front line view', and came up with solutions to a lot of these. For example, we looked at modifying the information on some of the HOT clinics that patients could be referred to on the system, and information on end of life pathways also difficult to access on the system.*

*We also looked through the current available information for ED clinicians that the palliative care consultant had developed, and I took this away and modified it to make a flow-chart for patients going through the ED that ED clinicians could use to contact the correct source of Palliative care advice at all times. This has now been incorporated into the clinical folders on all the ED computers so is available for reference for all ED clinicians. We informed one of the ED consultants who hopefully advertised this to the new doctors starting in February.*

*So all in all it was a very positive experience to be involved in, and we were able to follow up and start implementing some practical changes...*

E-mail extract from the GP trainee/ED registrar

The findings from the fieldtrip to Mount Sinai Hospital also had an influence on care delivery at St Thomas' Hospital. Plans and developments for a complete re-design of the ED commenced during this study, which meant that the ED leadership staff were reviewing and planning redesign efforts that this fieldtrip could feed in to. Chapter Five briefly stated that

the report (Blackwell, 2013) and design principles (Appendix 12) developed from the fieldtrip were provided to different senior staff at St Thomas' ED. One opportunity for this input was the co-design event, at which a senior nurse who was also the nursing lead for the ED rebuild project was present. He was given a copy of the report and design principles document and in the following e-mail extract he briefly outlines how they influenced plans for information sharing in the new department:

*'...As discussed your work certainly inputted into the wording on these slices with an emphasis of giving patients and relatives information regarding what they are waiting for, who to speak to about any concerns, what to do about food and drink.*

*We also are working on a 'fast track system' where patients such as palliative care patients who walk-in are fast tracked to majors for further assessment.*

*We are also developing 24 hour streaming so those patients will be identified as soon as they come into A&E...'*

Senior Staff Nurse

The information 'slices' mentioned refers to long banners that will line the walls of the new bed spaces in the rebuilt ED. They contain factual information about the department, waiting times and processes. The inclusion of this information speaks directly to the patient and carer concerns and those small but significant interactions that were so important to their ED experiences.

## **8.5 Influence and consequences of the study for wider clinical practice**

From the outset of this study the seeming dichotomy of older palliative patients in the ED has been made clear. While this thesis agrees with the commonly held opinion that this patient group would be better cared for away from the ED (Barbera et al., 2010, Scott, 2011), it has also provided additional insight to the growing body of knowledge that shows the role of the ED in acting as a net to catch palliative patients when community services fail, conditions become unmanageable at home and people are in crisis (Bailey et al., 2011b). In the narrative review of the literature (Chapter Two) the existing understanding of attitudes, knowledge and practice in the delivery of palliative care for older people in the ED was explored and the gaps were highlighted. A contribution of this study has been to provide additional data and understanding into these three aspects.

In discussing attitudes, this thesis has used exploratory narratives to try and unpick some of the complexities about attitudes towards palliative care in the ED, rather than presenting a theoretical discussion of how such attitudes are formed. Considerable literature exists on this subject and it is beyond the scope of this investigation (Olson and Fazio, 2001, McConnell et al., 2008). What this thesis does suggest is that the range of experiences of and attitudes towards palliative care means that there is unlikely ever to be a clear and united attitude about this philosophy of care, largely because of the range of world views and experiences that people carry with them. However, through the findings of this thesis it appears that some of the fundamental differences in attitudes are actually a direct result of a lack of clarity regarding definitions of palliative care. Each interview with patients, carers or staff provided a slightly different perception of palliative care. The previous chapters and DVD add to the evidence within the literature that some people consider palliative care to be an active exercise, while others considered it passive and the absence of action. While it would be imprudent to open a debate that suggests that attitudes can be wrong, it is possible that attitudes and experiences of palliative care could be ‘improved’ by the provision of accurate information and a shared understanding of what it actually is.

On entering the ED, patients and carers had different expectations of the department and the care they believed they would receive. Their expectations were influenced by previous experiences of healthcare and often by their own fears. The experiences shared by the patients and carers reflected their expectations and attitudes: Ann dreaded going to the ED as it indicated a deterioration in Alan’s condition; Barbara was angry and afraid as she expected to be ignored and Dave’s needs be overlooked; Angela and Manubhai trusted the staff based on the provision of information they received. This small sample, while not providing one clear answer as to the expectations of the ED by patients and carers, does demonstrate some of the complexity that ED staff are faced with. One of the carers, Ron, succinctly summed this up in his reflection that it requires a skilled nurse to manage the attitudes and fears of a person when they are seriously ill.

The narrative review implied that ED staff knowledge of palliative care was likely to be limited. Within this thesis the experiences shared by the ED staff corroborated this. For example several of the doctors and nurses could not recall having received formal palliative care education in their undergraduate training. Similarly to the finding that there was a mix of attitudes towards the ED and palliative care, this study found a range of skills and abilities in

staff knowledge of palliative care which seemed to be linked to an extension of compassion to patients and carers not routinely witnessed within routine ED care. Figure 82 contains a case example of this. The responses by other clinicians to the actions of the nurse in the example echoes findings from the narrative review about inconsistencies in staff attitudes and beliefs about palliative care provision in the ED.

**Figure 82: Case example showing inconsistencies in attitudes towards the provision of palliative care in the ED**

An elderly woman was admitted to resuscitation during a day shift. The full details of her condition were not made known but she was seriously unwell and the team decided to attempt resuscitation. After half an hour she was not responding and the senior nurse felt the treatment was becoming futile. The lady's husband approached the nurse and said they had been married for over forty years, would it be possible for him to lie with her and hold her as she took her last breaths. The nurse agreed and brought in a hospital bed to replace the resuscitation trolley. The patient was moved to the bed and the curtains drawn to provide privacy for the couple. As it was a quiet shift the nurse was able to dim the lights, reassuring the husband he was close by and would do all he could to support them. A short while later the lady died and her husband, on leaving her side, thanked the nurse for all he had done.

Once the husband had left the ED the nurse was berated by a senior medical clinician for his 'unprofessional' behaviour in 'allowing' the husband to be in the bed with his wife, regardless of the circumstance.

Palliative patient and carer experiential data regarding palliative care practice in the ED was missing from the literature, therefore, while bearing in mind that this study has a small patient and carer sample, its findings can offer insight into the needs of this vulnerable population in the ED that other departments may find useful:

- On admission to the ED patients and carers are often confused, afraid and in distress. Staff reactions such as welcoming behaviour, acknowledgement of the carer, and introducing themselves, could reassure the patients.
- Once in the ED, unless repeat attenders, most patients and carers were uncertain of what to expect from the ED staff and the ED itself. Their recollection of their experiences was influenced by information provided by staff and the manner in which it was provided.
- Staff experiences were influenced by the unknowns about the patients they were seeing. Ability to access key information about ceilings of care in a timely fashion was a major contribution to the ability of staff to provide the care required. Where

staff felt they were unable to understand and explore the patient and carers' needs, often due to time restrictions, they felt frustrated.

- 'Seeing the person in the patient' became a major theme and improvement priority from this work for the ED. In itself, this is not a complex concept. However, when staff feel pressure from targets and management coming down, and pressure from a number of patients coming up, many felt forced to become task orientated rather than, as the priority states, seeing the person in each patient.
- There was an interesting contrast between the expectations of patients and carers and the ED staff. Patients and carers wished to be informed in decisions and discussions about their care and treatment, whereas some of the staff, reflecting on their practice, observed a paternalistic attitude to older, palliative patients and their carers. Often born out of compassion, there was a reluctance to ask what were perceived as burdensome questions. There were assumptions that older people would prefer to be admitted to hospital, or that their admission was inevitable. Conversely, patients and carers were more confident in their assertions of what was their preferred place of care.
- Ultimately, patients, carers and staff alike were affected by the palliative care interactions in practice in the ED. The impact varied in its effect, but all participants expressed awareness of the changing needs of the older population.

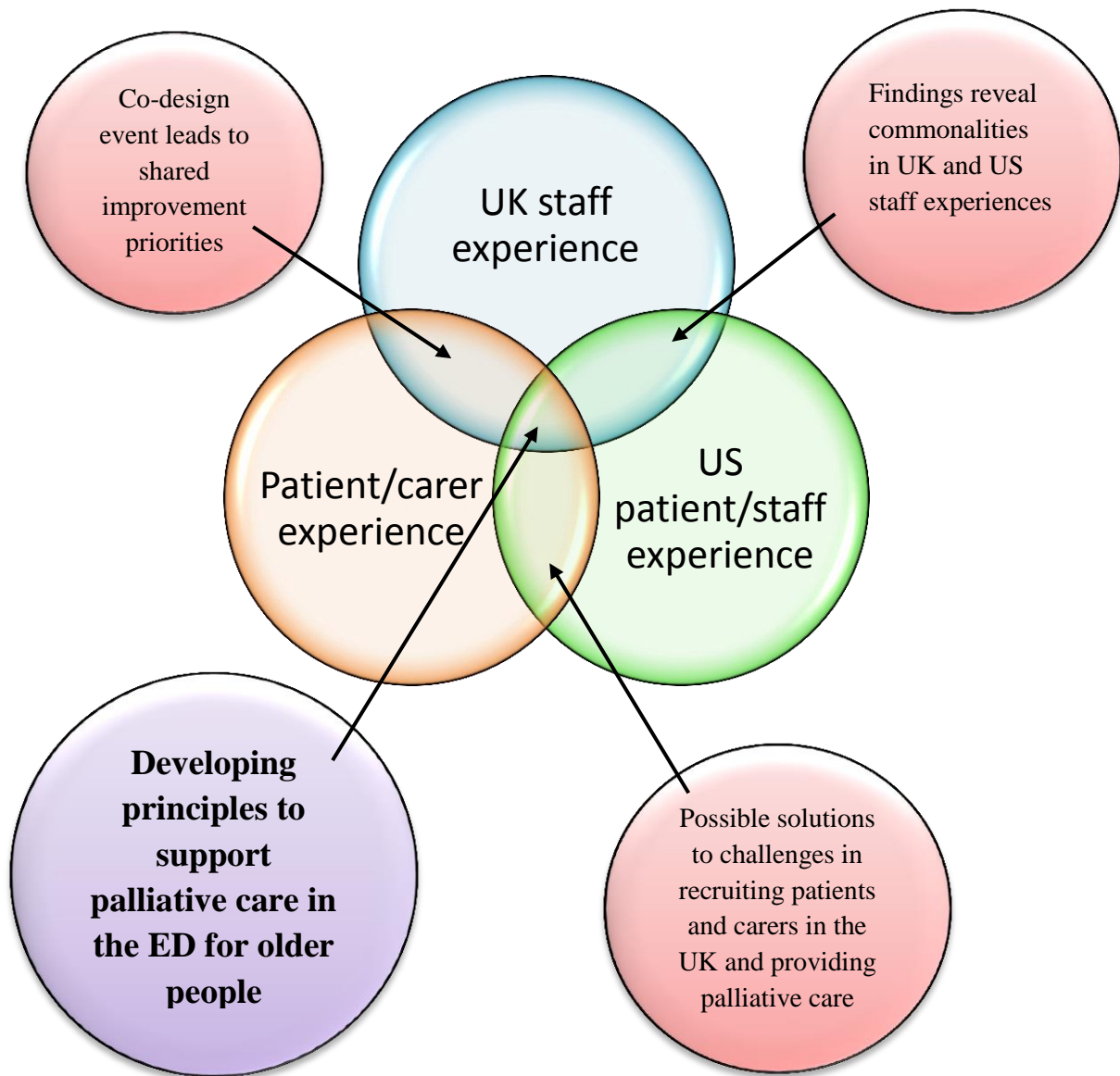
A second contribution of this study for practice is the accompanying DVD. The accompanying DVD can be used as a training tool for any ED, to trigger reflection and discussion. Its purpose is to encourage the viewer to ask of themselves 'How *can* these things happen? Is this my experience too?' This questioning maintains the ethos of inquiry and improvement with which the data were collected and that has underpinned this research.

In claiming the DVD is a contribution to practice it is important to address possible criticisms that the information may lose its relevance as practice evolves and develops, or have a limited 'shelf-life' when staff have viewed it. In response, the work of the accelerated EBCD approach provides useful insight. AEBCD used films, based on one regional service, at co-design events set in the same specialty, but recorded at different hospitals (Locock et al., 2014). The film evaluation feedback varied at different events as patients expressed if they agreed or not with the experiences shared. Regardless of their agreement, AEBCD concluded that the film's purpose was discussion leading to change, not consensus on experiences,

which are subjective (Locock et al., 2014). Based on this evidence, even as practice in the ED develops, the perspectives of the participants contained on the DVD can still serve as triggers for debate and review on *how* the service has evolved. A second response to the long-term usefulness of the DVD is based on an observation made by one of the ED staff interviewees. The ED has a very high turnover of staff which means that training and education needs to be routine. It also means that there will be an ever-changing staff body that will be new to the information on the film and that will arrive with their own experiences and perspectives. This factor also speaks to the longer term implications for maintaining behaviour and practice changes and improvements following EBCD projects. Furthermore the DVD will also be available to other departments and hospitals based on a signed agreement for the use, storage and management of the film.

The narrative now moves from the immediate contributions of this study for wider practice to recommendations for future research. When considering the contributions and findings of this study regarding the root of ED experiences, such as their triggers and the journey into the ED, it can be inferred that some changes may need to occur on a larger scale, for example in the core principles underpinning the management of older palliative patients. Figure 83 provides a visual representation for how this new thread emerged. The core of the Venn diagram contains the three elements of data collection within this thesis: the patient and carer story, the staff story and the US exploratory fieldtrip to Mount Sinai. In the first overlap Figure 83 presents the US and UK staff experiences that were almost identical, bar minor differences based on cultural factors and healthcare service design. Next is the overlap between the patient and carer experiences in the UK and the US fieldtrip. Here the UK story revealed challenges that were reflected in the observational data from the US. In addition, the US data provided insight into possible ways for improving service delivery that could be extrapolated to the UK. The final and most important overlap in the diagram is that of the staff and patient/carer stories, whereby a shared narrative emerged leading to collaboratively agreed improvement priorities.

**Figure 83: Study findings implying potential design principles that could improve palliative care delivery in the ED**



This thesis suggests that there are core design principles for the delivery of palliative care in the ED for older people that are at the root of providing a positive experience based on critical reflection of these overlaps and shared experiences. Building on the findings of this thesis and the improvements and changes made as a result of its influence, coupled with the developing work from the US, three provisory suggestions are offered for what these design priority principles are:

1. Communication and information
2. Systems and processes
3. Training and education

These are not new ideas or concepts. Recommendations for each in the provision of palliative care can be found within this study, as well as across palliative care literature (Beckstrand et al., 2008, Smith et al., 2009, Bailey et al., 2011b), and in design science literature (Plsek et al., 2007). However, recommendations are often quite vague, or are proffered with further questions attached to them, such as, ‘What are the training needs?’ and ‘What areas require greater communication?’ (Quest et al., 2011). This section concludes with a series of provisory recommendations for the three design priority principles. They once more build on the staff, patient and carer experiences and the subsequent changes being made in St Thomas’ ED, while also drawing on the literature base supporting this study, and the findings from Mount Sinai.

#### **8.5.1 Recommendations for implementing the core design principle: communication and information**

More information needs to be provided to patients and carers about the ED on their arrival to alleviate stress and fears about ‘bothering’ staff with questions. This includes details of routine information about waiting times, such as for tests and test results. Once in the ED, there needs to be on-going communication and inclusion about decision making with patients and their carers. This refers to matters relating to clinical care delivery, but also the small but significant matters for example, where the cubicle curtain is placed, or being offered a drink or sandwich. Throughout the ED visit on-going communication with patients and carers about what is happening provides reassurance. If the ED visit has been initiated by community services, patients and carers need to be informed of what information to bring to the ED.

#### **8.5.2 Recommendations for implementing the core design principle: systems and processes**

Improve communication and provision of vital information with the patients to the ED from community services and nursing homes which may assist with ED to care home discharges. To improve the experiences of the ED for older palliative care patients develop specific systems that prevent negative outcomes resulting from the four hour target. Possible systems include frailty units, different triage models, specific assessments, and use of specialty clinicians who are ED-based, such as geriatricians or palliative care clinical nurse specialists. In addition ensure that I.T. platforms within hospitals link up, or that there are electronic flagging systems to enable ED staff to be able to access vital patient information, for example resuscitation preferences, end of life conversations or specific teams providing routine care. While in the ED, consider using volunteers to provide for non-clinical needs of older



palliative care patients and to support clinical staff. Develop clinical pathways from the ED to other wards for patients admitted due to social or psychological reasons (theirs or their carers), for example inpatient palliative care units. To ensure ED staff knowledge of palliative care services, or other specialities that have patients who can present in terminal crises, e.g. respiratory, cardiac, oncology, renal, maintain mandatory routine updates.

### **8.5.3 Recommendations for implementing the core design principle: training and education**

When planning palliative care training and education for ED staff, include patients and carers, and consider inviting patient and carer representatives to speak with staff. Developing this type of bespoke ED palliative and end of life care training is likely to be more helpful than generic end of life care training, due to the differences between the ED and inpatient wards. Suggestions for bespoke training include indicators for terminal condition deterioration to help develop better transitions through the ED. Instead of usual ED reactive approach encourage use of tools such as the ‘surprise’ question: *‘Would you be surprised if your patient were to die in the next 6-12 months? This is an intuitive question integrating co-morbidity, social and other factors’* (Thomas and Free, 2006). This question prompts the clinician to look beyond the four hour window of care in the ED to the bigger picture of the patient’s condition and palliative care preferences. As well as implementing practical training around hydration and pain with easy access to palliative services to support this, also develop ‘soft skills’ that can help ED staff to focus on the psychological needs that may underpin many of the admissions. Offer externally provided support as well as building team support as part of a training programme. Facilitation by skilled palliative care staff with understanding of the ED could serve as a means of encouraging reflective practice and helping staff to draw on and learn from personal experiences.

This section shows that the study has raised questions and suggested that there are ways of developing the existing model of ED while contributing additional information to the existing body of knowledge. As this was a small study in one department and the concept of underlying design priorities is newly emerged there is considerable scope for further research to explore these recommendations, but also to pose the following questions which arose during this study:

- Have the changes improved experiences for patients, carers and staff, and if so, how?
- Does the use of the DVD contribute to ongoing behavioural and attitudinal change in ED staff?
- How can patients and carers in the community be educated about the role of the ED and the most useful information to bring in case of emergency, without causing distress?
- Are the findings from the study recognised at other sites in urban and rural populations?
- Do the shared improvement priorities translate to other palliative conditions?
- Do the shared improvement priorities translate to all cultural and ethnic groups?

A post-doctoral study will continue exploring these issues.

## **8.6 Influence and consequences of the study for policy**

As this research progressed there was a growing trend across agendas that emphasised the involvement of patient and carer user groups in efforts to improve experiences of healthcare provision. This was found in the threads that ran through this study: care of older people including palliative care specifically for older people (Hall et al., 2011, Leadership Alliance for the Care of Dying People, 2014a, Marie Curie, 2015), and the ED and older people in the ED (Banerjee and Conroy, 2012, College of Emergency Medicine, 2013). There was also an increasing recommendation for services to become more joined up to ensure consistency of care provision (Banerjee and Conroy, 2012, Involve, 2012b, Naylor et al., 2013).

Changing attitudes and increasing cross-specialty working was certainly observed at GSTT, for instance in the examples presented previously such as the geriatrician-led frailty unit in the ED, and greater palliative care team involvement in ED training and education. However, it was also observed that when unexpected incidents arose that shook existing practice, the immediate outcome appeared to divide services, rather than draw them closer together. This seemed to be particularly the case when ‘crises’ were the result of pressures from groups with limited understanding or concern for the existing processes, such as the media. Key examples for this thesis are once again the national removal of the LCP from clinical practice and the concerns over ED waiting times.

While the removal of the LCP has undoubtedly led to greater opportunities for more research and discussion of death and dying issues, the pressure on those leading palliative care and end of life programmes for the UK meant development of an immediate response. Regrettably the response is not particularly useful to an environment like the ED. The negative impact on care for older people in the ED based on the time pressure has also been discussed. It can be extrapolated that the new requirements to develop individualised care plans without using terms such as ‘pathway’ or ‘guideline’ (Williams, 2013) is intrinsically challenging for the ED which relies on easily understood and rapidly implemented processes. In instances like this, the slowly evolving culture that is inclusive to the needs of those using the service, the concerns of those providing it, and the requirement for skilful management of different agendas and priorities becomes threatened.

The claims of an ED ‘crisis’ were a particularly difficult factor to contend with in conducting this study. The observations of the ED for this study focused solely on one department in one hospital, but were strengthened by what evidence could be found in the literature which suggested that the media and political claims were to some degree hyperbolic. Although some staff did report distressing experiences, and time was a significantly challenging factor for them, the ethos of care witnessed belied the manner in which the ‘crisis’ was presented. However, the observations made within this study could not reasonably be reported as unquestionable evidence. Interactions with patient and carer participants, as well as with members of the public or other healthcare specialities were challenging, as they were unsurprisingly influenced by the media and political reporting. They placed what seemed to be undue blame on the ED and ED staff for ‘failures’ in the NHS. This unbalanced focus on the role and remit of the ED in the patient journey compared to the rest of the healthcare system was acknowledged in the official report exploring the apparent failure of EDs to meet the target waiting times (Blunt et al., 2015).

It was with relief that the findings of the recent Nuffield Trust report into the situation drew the attention to the wider health system, and advised against placing blame on the EDs for failure to meet targets (Blunt et al., 2015). The four hour ED discharge target was brought into the system for good reason – to stop twelve hour waits in the ED, as discussed in Chapter One. Regrettably the target does not make allowance for the increasingly complex conditions of older patients using the ED. This group need more time than this target allows, which is particularly challenging when seen in conjuncture with the demands and needs of other patients. By highlighting the impact on the ED of restricted hospital bed spaces, instances of

inappropriate, unsafe discharges and disconnected community services leading to readmissions, the ED ‘crisis’ can be viewed more rationally and responded to appropriately. The timely publication of the report for the writing of this thesis draws the ED back into the health system, warning against silo working in the NHS.

At the present time different organisations in emergency, palliative and geriatric medicine are working hard to meet the challenge of a population that is growing older. Each of the organisation’s individual agendas state that services need to be more inclusive of each other and there is evidence of some overlap and different locally piloted models (Banerjee and Conroy, 2012). However, based on the evidence of increasing use of the ED by older palliative patients, it is a recommendation of this thesis that a new approach be taken that includes a core group of patients, carers, and practitioners with representation from each of the specialties mentioned above. Working inclusively such a group would develop greater sharing of services, improvement of working relationships that includes patients and carers, and redesign of the traditional ED model to meet the emerging needs of the changing population.

## **8.7 Influence and consequences of the study for EBCD**

Before attempting to offer any recommendations or implications for the wider body of knowledge on EBCD, it is important to address the adaptations made to the approach, as some could reasonably question if the adaptations affected the validity of claims that this was an EBCD research project.

One of the first challenges encountered concerned starting the project at a time when the full extent of the research problem was not fully recognised by the study site. This subsequently prevented dual data collection of staff and patient-carer experiences concurrently as per the usual running of Stages 2 and 3 of EBCD projects. In addition conducting the study as a lone researcher and PhD project external to the study site meant there were limited time and resources. Being an external facilitator to the site also challenged the ease with which staff could take ownership of the research.

There were specific challenges to conducting the study with older palliative patients and their carers, some of whom were bereaved. This prevented the desired degree of ownership and involvement in the processes, which exacerbated a recognised challenge for health service

EBCD projects (Bowen et al., 2013). The frailty and vulnerability of the patient and carer group also meant the absence of a patient and carer shared event to view the trigger film prior to the co-design event. This is an important feature of EBCD projects which helps to develop relationships, trust and further ownership of the research process for patients and carers (Donetto et al., 2014).

Timing was a challenge and limitation for the EBCD process in this research throughout its duration. Most EBCD studies take 12 months (Locock et al., 2014), whereas this study took three and a half years. It was further extended by the inclusion of the US fieldtrip. The time limitations ultimately meant that the study culminated at Stage 4, excluding ongoing co-design working in Stage 5 and the celebration event and review in Stage 6. Concluding the study earlier could impact on longer term behavioural change and cyclical improvement work (Donetto et al., 2014).

In response to these limitations one of the main benefits of EBCD can be drawn upon; its flexibility and adaptability to different healthcare challenges within fundamentally different clinical areas. In Chapter Three, adaptations that other projects have made were presented and their rationale critiqued (Donetto et al., 2014). This included the successful creation of an accelerated approach (Locock et al., 2014). Other adaptations to the approach have been exclusion of non-participant observation or a patient-carer trigger film, and use of focus groups in place of one-to-one interviews (Donetto et al., 2014). To manage a project based in a busy ED and including people who are approaching the end of their lives, it has been stated that a theoretical framework was needed. However, the various challenges that the topic and the participant groups presented meant that flexibility in the framework was vital. In response to this very challenge came a suggestion from the review of EBCD:

*‘Be flexible: look for ways to adapt the approach to fit your service and purpose. A long process can be burdensome particularly if only one person is managing the project.’* (Donetto et al., 2014, p.38).

Furthermore, while the study did not follow the anticipated timeline which would have included Stages 5 and 6 of the EBCD process, the slower progression of data collection coincided with the social and politically based clinical changes to the LCP discussed previously. With this in mind the limitations and criticisms can be answered with the EBCD features that were included, and the rationale and management of the necessary adaptations

made. First, attention can be drawn to the core elements of an EBCD project that were included in this thesis:

- Staff experience data collection, validation and collaborative selection of improvement priorities.
- Patient and carer filmed data collection, validation and collaborative selection of improvement priorities.
- Non-participant observation and supportive fieldwork data collection to provide additional contextual data.
- Creation and use of a trigger film.
- A co-design event leading to development of shared improvement priorities and subsequent improvements to palliative care delivery in the ED, despite the study officially concluding at Stage 4.

There is a risk that the absence of Stages 5 (on-going co-design work in small groups) and 6 (celebration and review event) could impact on continued ownership of practice improvements. However, from the early changes presented in later in this chapter, improvements appear to be gaining momentum, as this study complemented a wider departmental focus on ‘soft skills’. In addition, although there were challenges related to working as an external researcher, a comment via an e-mail from a palliative care consultant highlighted one of the benefits of this position:

*‘From my perspective, as a person unfamiliar with action research, it’s been interesting to see how your contact with the emergency department, being embedded with them and thus understanding their needs, has opened doors which on our own we had been unable to do.’*

Palliative Care Consultant

The main reason for adapting the conduct of the EBCD process was to ensure ethical conduct in working with the vulnerable palliative patient and carer participant group. It might have been simpler to work solely with carers of terminally ill patients, but the inclusion of this patient group within this thesis was vital to the process of improving palliative care in the ED. This is a particularly poignant point in light of the removal of the LCP and reports that palliative patients and carers are often excluded from discussions and decisions about their care (Williams, 2013, Leadership Alliance for the Care of Dying People, 2014a). However, an important addition to this thesis, documented at the conclusion of the epilogue, is the later

completion of Stages 5 and 6 of the EBCD process which were undertaken following the completion of the writing of this document and serve to strengthen the wider body of work.

The flexibility of the EBCD process became its greatest strength in ensuring that the patients and carers were given a voice to say what palliative care meant for them in the ED, shedding light onto how ED staff needed to be trained and where the ED needed to adapt its model of care. The absence of the patient and carer event was regrettable, but its inclusion would have placed an inappropriate burden on the participants. Carrying out the data validation processes with patients and carers on a one-to-one basis instead of a shared event was emotionally charged and often draining for me. Despite this, it was a price worth paying to ensure that some degree of ownership and control over the data remained with those who had provided it. The small representation of patients and carers at the co-design event was based entirely on their condition deterioration, and those who could not attend expressed their regret. However, the use of the trigger film served as a powerful way of allowing their opinions and experiences still to be heard.

The challenge of conducting this thesis as a lone researcher have been referenced at length, but here again there were benefits. Although this study was born out of personal experiences and observations from clinical practice it was demonstrated that ultimately, the ED staff took ownership of the research findings, and are working with them to improve palliative care delivery. Though in retrospect it would have been preferable to have been more closely aligned with the ED, the perspective as an external observer and facilitator allowed insight and an objective stance that was beneficial to the analysis process and co-design event.

To meet the aim of an EBCD study it is necessary to focus analysis on the understanding and expectations of the experiences identified by the participant collaborators. Specifically the analysis presented needed to remain faithful to the experiences of the ED staff, patients and carers. Using this approach within a doctoral study therefore limited a more traditional theoretical analysis of the data. This criticism could also be aimed at EBCD more generally as the requirements of conducting a PAR study with a defined outcome of service improvement, means that rich data may not always be analysed to its full theoretical potential. Although some reference has been made here to the ontology and epistemology of EBCD in Chapter Three, and in relationship of the findings to wider professional and academic literature earlier in this chapter, the limits to wider social theory in this thesis is acknowledged. Thus the findings presented focused on the improvement priorities identified

by the participants, rather than exploring more fully the eight themes emerging from the original staff interview data and the five themes from the patient and carer interview data.

The initial analysis that identified these thirteen themes was restricted to identifying the themes and presenting them for validation in order to look practically for clinical change potential. Having completed the EBCD study it is now possible for further analysis of the data to explore the themes more theoretically.

One example is the theme ‘age’, identified as a barrier to the provision of palliative care throughout the staff interviews. The transcripts revealed a degree of stigmatisation towards older people in terms of decision-making, and involvement of the patient in decision-making. The theoretical analysis can be expanded to investigate further the phenomenon of older people with full mental capacity being excluded from decision-making processes at the end of life in the ED (Le Conte et al., 2010). Staff spoke openly and honestly during their interviews about their perceptions of the needs of older people in the ED, and acknowledged they were less inclined to engage an older people in decision-making processes, or even to ask ‘how are you’ as there was not time to respond to the ‘can of worms’ they believed this type of open question would elicit. Some staff acknowledged their different reactions to the death of an older person compared with the death of a younger one.

Butler’s Theory of Ageism (Butler, 1969) can provide a lens through which the staff data can be further analysed to generate deeper understanding of staff attitudes, reactions to and the impact occurrences such as death in the ED have on staff and their ability to navigate such occurrences during the course of routine practice and care.

To give another example, from the initial patient and carer interview analysis a theme that emerged was that of the changing ‘culture’, referring to various aspects of life discussed during the interview that were altering beyond the control of the patients and carers. The word ‘culture’ was originally used to describe this theme as it encapsulated the broad spectrum of changes discussed by patient and carer participants, such as deteriorating and unpredictable health conditions that were altering expectations of daily life and leading to declining physical abilities. In addition the relationships between the patients and carers, or patients and other people were also in a state of flux, and this change to their ‘culture’ related to how the participant group felt they were treated by other people. The theme was later portrayed as ‘changing experiences’ to better represent the understanding of the theme by the



participants. This theme of ‘changing culture’ contains rich insight into the lives of the patient and carer group, as their health conditions and therefore lifestyles change without their control and sometimes without their understanding. Transitions Theories can enable a deeper understand of the experiences shared, for example lifeworld changes that end in the diminishing of one’s capabilities (Ibrahim Melesis, 2010). Cross analysis of the patient and carer and staff data using Transitions Theory can provide insight into where and how ED staff could offer support to this patient and carer group during the different challenging transitions caused by terminal illness (Ibrahim Melesis, 2010). To counter the lack of application of broad social theory to the analysis of the data and thereby broaden the scope of this thesis, a list of proposed publications has been developed to allow for the theoretical analysis of the data and exploration of findings that emerged through the research process, that could not be fully presented without deviating from the retelling of an honest narrative (Appendix 33).

Having responded to the challenges and limitations of undertaking this project the discussion now moves on to consider the implications and contributions that this research offers to EBCD.

A recent report exploring EBCD concluded with an invitation to EBCD researchers to share their thoughts on various aspects of using this methodology (Donetto et al., 2014). One aspect of the invitation concerned the nature of critical thinking needed to increase the impact of co-design approaches in healthcare settings. Chapter Three presented the conceptual framework developed to aid the conduct and critical understanding of this study. The purpose of the conceptual framework was to critically deconstruct the concept of experience so as to reconstruct it as it applied to the research challenge of this work, and the conduct of an EBCD study. The framework placed an emphasis on exploring and identifying the expectations and understanding of the patient, carer and staff experiences, in order to draw out touch points that would lead to improvement priorities.

The assertion of this thesis is that this approach to the theoretical presentation and deconstruction of the methodology could be applied to other EBCD projects. During the data collection and analysis fascinating tangents emerged that the research could explore, as well as a wealth of rich data. The conceptual framework’s explicit focus on expectations and understanding helped to maintain boundaries by recalling the threads of investigation back to the research question.

A second invitation from the EBCD report was to identify data on how individual projects add to well-established quality improvement processes in organisations as large and multifaceted as the NHS (Donetto et al., 2014). An implication from the thesis for future EBCD projects is its capacity to manage complex and occasional contrasting participant groups and challenges. Chapter Three discussed that EBCD has been used separately in oncology, care of the elderly and the ED. This thesis recognised where these three threads had become interwoven: a complex patient group, with ambiguous but urgent needs in a busy and fraught environment. The evaluations from the co-design event (Chapter Seven) and the feedback regarding early consequences and changes in practice (presented previously in this chapter) demonstrate the scope for the use of EBCD in marrying the needs of multiple complex factors to lead to quality improvement processes in complicated and busy environments.

## **8.8 Personal influence and consequences of the study**

The narrative now turns to the personal reflection and critique of the external and wider influence and consequences of undertaking this study. A development log was kept throughout the process recording different opportunities that arose over the four years of carrying out this work from 2011 to 2015. This record is important as it demonstrates interest in care of older people with palliative care needs in the ED beyond the research study site, which resonates with the previous section exploring the implications of this study for wider practice. The opportunities were diverse and either influenced the conduct of the study, or provided avenues for me to exert an influence through early dissemination. In the latter category the interest in this work also emphasised how little is known about the lived experiences of patients, carers and staff in the ED. The following discussion reflects on this aspect through key conferences, teaching and networks I participated in. The full development log can be found in Appendix 34.

Over the duration of the study I attended eleven conferences and seminars as a delegate, and presented at an additional twelve conferences or meetings. I was able to present at two conferences that held specific significance for this study. The first was organised by NHS Improving Quality. This conference ‘Route to Success – Transforming End of Life Care in Acute Hospitals Conference’ was held in March 2014 and I presented a seminar entitled ‘End of Life Care in A&E’ (Appendix 34) during which I was able to share the findings that had

been validated by staff in the study and the findings of the fieldtrip to Mount Sinai. This was a national conference that was part of the National End of Life Care Network movement, the work of which has informed the study throughout its duration. Being able to present at this event provided a national platform to disseminate the early work of this study and to develop key networks and contacts for future collaboration.

The second conference ‘Compassionate death in hospital’ was organised by the National Council for Palliative Care in February of 2014. At this conference I presented the findings from the staff data drawing out the struggles and challenges they experienced in trying to provide high quality palliative care in the ED. After the presentation I was invited to sit on a discussion panel to respond to questions about compassionate care for the dying in hospital. This was another important platform as the audience were predominantly from palliative care environments. I felt this was an opportunity to raise the profile of the ED as it is often overlooked as a provider of palliative care and a part of many patient and carer’s journeys through the healthcare system, particularly at the end stages of life. Although I was limited in the degree of detail I could share at these events I was often surprised by the interest the study generated and the requests to be kept informed via e-mail or as presentations and publications following its completion. This external interest helped to keep my focus on the wider story of a national and international challenge, considering and gauging an understanding of the transferability of the study findings.

Invitations to teach on the findings of this study and topic area was unexpected opportunity that grew over the course of the research (Appendix 34). Predominantly teaching was provided to staff at St Thomas’ ED. This proved to be a useful method for encouraging interest and engagement in the study during periods where I was involved in off-site activities such as data analysis. Towards the completion of the study I was invited to teach on the MSc A&E course at King’s College London. As with the conferences, I was not able to share all of my findings at that stage. However, these teaching sessions in were of particular value in exploring the transferability of the findings and experiences of the study participants to ED nursing staff from other NHS hospitals. I chose to show short segments of the DVD which, based on evaluation forms for the sessions, resonated with the nurses attending the course. Figure 84 contains comments taken from some of the evaluation forms, which asked how useful the session was, and to what extent the content could be applied to clinical practice. The response was unanimously positive and the comments below were reflected through all

of the evaluations. The use of the DVD in particular was an effective means of communicating the small but significant needs of the patients and carers, such as reassurance given by eye contact and a smile, or offering a drink. The purpose of the DVD is to trigger discussion and reflection leading to service improvements where needs are identified. This is what the nurses expressed they had experienced within the teaching session in their feedback.

**Figure 84: Extracts from palliative care in the ED teaching session evaluation forms**

<p>‘Film was excellent, made me evaluate my own care’</p> <p>‘Raised awareness about palliative care...influenced myself to try and improve all patient experience’</p> <p>‘Gave me an informative concept of what more I can do as a nurse. It’s the simple things that make people happy’</p> <p>‘Excellent presentation! Extremely useful and prompted a lot of thought on how A&amp;E and I can improve care for palliative care patients. Loved the video. Thanks.’</p> <p>‘Recognising end of life patients who may not have previously been immediately obvious and making small changes to practice to provide ‘specialist’ care.’</p>
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As the study progressed I was able to develop a network of different clinicians and organisations in the UK and internationally. These emerged through attendance or presentation at the different conferences, events and presentations listed in Appendix 34, or via other clinicians and researchers, and latterly through e-mail contact based on publications.

Developing networks became an important secondary activity while the study was being conducted as they offered support and connections that influenced my conduct in the study, and future planning. A prominent example was the support of the Florence Nightingale Foundation (FNF) (Appendix 34). Their initial funding provided for the fieldtrip to Mount Sinai Hospital. On my return I became more involved with the FNF, for example working as steering group member of their Alumni Association Steering Group. This activity and the contacts I made through the FNF enabled early dissemination activities, such as meetings with senior staff from different organisations and hospitals interested in this study as it related to challenges they were experiencing.

## **8.9 Conclusion**

In this chapter the different threads and activities have been picked up and woven together to reflect on the influence and early consequences of this study on the participants, research site, wider practice and policy. The story of this work is drawn to its completion in the following epilogue.

## EPILOGUE

The prologue to this thesis made explicit the chronological narrative, and Chapter Three presented and critiqued the interpretative-constructivist paradigm that guided and underpinned the telling of the research story and researcher's story. The story of the research project was concluded in the previous chapter. This chapter serves as the epilogue to this thesis, told solely as a first person narrative. Here, my personal story is drawn to a close with a critical and self-critical reflection and conclusion.

When I started this thesis I could not have anticipated the startling developments in palliative and emergency care, or the route from which they emerged. However, in Chapter Three I detailed that part of the rationale for using an Action Research (AR) approach was its capacity to encapsulate topics that have unknown or changing parameters, and stated that one of its pre-requisite traits is the acknowledgement and use of different world views (Zuber-Skerritt and Fletcher, 2007). This allowed me the theoretical space to reflect upon the perspectives emerging from the media and political bodies, and to consider their implications for this thesis. I observed that an AR approach, even within a methodology like EBCD that contains staged processes, can develop in unexpected directions (Zuber-Skerritt and Fletcher, 2007). Indeed among the indicators for a 'quality' AR project is the demonstration of different forms of knowledge drawn on within the research (Meyer, 2007). Within this thesis 'knowledge' has been drawn from the staff, patient and carer participants, but also the work at Mount Sinai, the wider literature, and latterly, media and political reports.

I have attempted to maintain a conscientious and comprehensive critical audit and reflection on the processes, decisions and influences on and of this thesis. My own views on the findings from staff, patient and carer data, as well as the external social changes that influenced the palliative care and ED threads of this thesis, have been expressed in the reflections within each chapter. A particular challenge has been managing the transition from nurse to researcher and I have questioned, as others before me have, where does one role stop and the other start? (Bailey, 2007). However at the root of these challenges and reflections my concern has continually been to move closer to meeting the aim of this study, to improve experiences of palliative care in the ED for older people, their carers and staff.

Where staff, patients and carers expressed views I did not agree with or expect I have been surprised by my perplexity. Where media influences have been misinformed or lacked insight

I have found this personally quite difficult and frustrating. However, the methodology and interpretivist-constructivist ontology and epistemology that this thesis sits within has helped to bring balance to my reflective processes. It has served to continually remind me of the importance and value of other perspectives. The strength of my own convictions and my early paternalistic and medically minded focus was counteracted by the processes of EBCD. This included the implicit quality indicators within the approach that called for ongoing critical reflection, equal involvement and empowerment of participants, and rigorously monitored and reported practice in the conduct of this thesis (Zuber-Skerritt and Fletcher, 2007).

The methodology also prompted and allowed the process of critical reflection, which was vital to the integrity of the conduct of the study. As the main facilitator and driver for the work it was imperative that I retained a sense of self-awareness, taking time during each phase of the EBCD process to stop and reflect upon the influence of my role on the study, but also the influence of the study on me. As first discussed in the Prologue, I drew on the reflective models of Gibbs (1998) and Johns (2013) as I have done since my early nursing days which was a useful and familiar way of ensuring this critical reflection took place. Indeed, critical reflexivity is an intrinsic part of the nurse's role be they clinician or researcher (Topping, 2006). These models provided a framework for my critical reflection to be held within, where Gibbs' Reflective Cycle (Gibbs, 1998) provided the main structure for my reflections and a pathway to move through during the practical research processes. The audit logs written at each stage of the research process with pertinent extracts provided throughout the thesis are evidence of my critical reflection and the application of this theoretical model to my practice. Each log provided a description of the incident, highlighting how I felt, positive and negative aspects, making sense of the incidents, and looking at what else could have been done to plan ahead to improve each activity. The critical reflection provided at the conclusion of each chapter drew more fully on the reflective development work of Johns (Johns, 2013). These expanded upon the early reflections of the audit logs in more depth, allowing me to consider the emerging narrative as it related to my own role as a nurse becoming a researcher, as well as to my own understanding of self within this process. The first person reflections included in this thesis were provided to enhance the reader's understanding of the story of the research and the impacting forces on the study processes. However, it was important that I did not become so involved in my own reflexivity that the story of the study and the experiences of the staff, patients and carers became secondary.

Furthermore, due to the time constraints of conducting this study to deadline, further discussion and critique of my role has been reserved for publication rather than woven throughout the thesis, which a more traditional telling of a thesis may have allowed.

In critically reviewing the reflexive processes there is another challenge that must be highlighted: that these processes were conducted alone. This resulted in occasions where my conclusions were overly critical, or I was unable to recognise all of the nuances in each situation. At these times the monthly supervision sessions provided a much needed balance to the reflections, giving me the opportunity to discuss my understanding of the data, and to expand my understanding by learning from other perspectives. For example, as stated in Chapter Four, while conducting staff interviews during the Stage 2 of the EBCD process I was encouraged to reflect upon my interviewing technique as my supervisors noted my difficulty in allowing staff to express ‘wrong’ opinions of what palliative care was, or failing to explore their responses in more depth. Another example discussed in Chapter Six occurred during the patient and carer interviews, where my concerns for the wellbeing of different potential participants threatened to lead me to overstep the boundaries of my role as a researcher. Here again I was encouraged to take time to reflect upon my role, the wider situation of each participant and to think about the implications of different courses of action, as well as to begin counselling to process the distressing scenarios I was encountering.

While my own critical practice and the audit logs had identified a narrative through these processes and highlighted challenges, sole reflective practice without accountability and support would have prevented a thorough reflective process. While the style and presentation of this thesis is unconventional, it allowed the narrative of the research as well as my own story to unfold in an honest retelling, and as Johns writes:

*‘The beauty of story is the way it can illuminate the contextual meaning of complex theory in ways the reader can sense in relation to their own experiences. Story draws out the subtlety and nuances of facing from its apparent mundaneness and its significance within healthcare...Writing in a more traditional style would be a contradiction to what I view as the essential nature of reflective practice. It would only reinforce the idea that reflective practice is a technology with specific techniques to apply...The reflective practitioner has an open and curious mind in order to be receptive to what the text has to say...’*

(Johns, 2009, p.xiv)



The methodology also served to highlight the value of another key trait of AR projects; closure of the knowledge gap on a given topic between a small group of scientists and the wider society (Zuber-Skerritt and Fletcher, 2007). The taboo nature of death and dying has meant that many of the care processes provided in the ED are misunderstood by members of the public. There are many challenges in engaging ED staff and palliative patients and carers to discuss what their needs are, as well as understanding their experiences. I believe that the use of the DVD generated by this study acted as a catalyst at the co-design event that broke down barriers between the healthcare staff and patient and carer participants. It enabled a collaborative exploration of the challenges faced by ED staff in the provision of palliative care. This then allowed the group to be led to discuss improvement activities that benefited all parties involved. Were the health system better understood, and the decisions and processes undertaken by healthcare staff within them better communicated to the public, it is possible that many of the distressing experiences reported in the review of the LCP and media that were reflected in the concerns of this study's participants could have been avoided (Williams, 2013).

Essentially my personal experience is similar to the main research account of this thesis. Both started out as stand-alone narratives but have developed into a contributing chapter to a much wider story. The aim of this thesis has not yet been fully met, but the findings to date suggest that, where palliative care admissions to the ED do occur, they can be improved and made more positive for those involved. My assertion is that there is considerable scope and opportunity for further exploration, development and evaluation.

## **Conclusion**

In concluding this thesis I acknowledge that there is a great deal more work to be done before the claim can be made that experiences for older palliative patients, their carers and staff have been improved in the ED. What this thesis has provided however, is foundational data on the types of concerns the three groups have, as well as greater detail on their needs, experiences and future hopes for palliative care delivery in the ED that was missing from the literature. It has demonstrated that EBCD can serve as a powerful method for effecting change with the involvement of patients, carers and staff, even in an area as busy as the ED with patients who are elderly and terminally ill. The outlook for palliative care for older people in the ED is still uncertain, but this thesis shows that the three separate but intertwined threads can work

together effectively. This is an important finding and one that strengthens the ongoing aim for the future work of this research: to improve experiences of palliative care for older people, their carers and staff in the ED.

## **Postscript**

The thesis was completed and submitted for examination in May 2015. Subsequent to this, Stage 5 (ongoing co-design work in small groups) and Stage 6 (celebration and review event) of the EBCD process occurred organically. To offer a complete retelling of the narrative of this study these latter Stages are presented here.

### **Stage 5: Ongoing co-design work in small groups**

Several members of the patient and carer participant group had expressed their willingness to remain involved in the developmental work for improving palliative care at St Thomas' ED. The opportunity to facilitate this occurred during a final feedback session provided to a number of staff at the ED at the request of clinical lead. The session comprised a viewing of different parts of the second version of the DVD and a facilitated discussion for staff to further identify what changes and improvements they could make within the department. Within the discussions some of the staff commented on how helpful various comments made by the patients and carers were. Out of this session I was able to facilitate an introduction between the clinical lead and one of the carers, demonstrating willingness for ongoing working groups. My role as the study facilitator was complete at this point and I was able to hand over the findings and DVD for staff, patients and carers to continue working to improve their experiences.

### **Stage 6: A celebration and review event**

The celebration event marks the conclusion of a typical EBCD project. Due to the challenges outlined throughout this thesis, I had acted as a facilitator working between the staff, patient and carer groups who were restricted in their degree of involvement by ill-health or clinical requirements. Following the completion of the thesis, the dissemination event referred to in Stage 5 also served as the celebration and review event for the staff. Prior to the event I had given a thank-you card, fruit and chocolate to the department in recognition of their involvement and input. The dissemination event provided a wider staff audience comprising

ED doctors and nurses of different grades to be informed on the findings of the study and future plans, as well serving to promote the ongoing co-design work.

Celebrating and reviewing the study with the patients and carers also took on a different format to the traditional approach, but followed the conduct of the preceding stages of the study where I worked with them largely on a one-to-one basis. When the second version of the DVD was completed I contacted all the participants to enquire if they wanted me to post or hand deliver a copy of this film and delivered them as per their preference. I then composed individual letters to each participant, thanking them for their involvement and outlining how their unique experience had fed into the study and my plans for future work. I also informed them of the early and proposed changes to practice at St Thomas' ED. Given the rich data and personal experiences that each participant had so willingly shared, this appeared to be a fitting way of marking their involvement and celebrating their participation. It is in keeping with the thesis that these two final stages took place unconventionally, but fitting that their occurrence happened when they did, providing closure for all involved on this chapter of much larger and ongoing body of work.

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## **APPENDICES**

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Appendix 4: Interview field notes and detail

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### Chapter Five

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## Appendix 1: Staff information sheet

### INFORMATION SHEET FOR PARTICIPANTS – A&E Staff



REC Reference Number: [PNM/11/12-57](#)

### YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

#### Improving the Experiences of Older Palliative Patients, their Carers and Staff in Accident and Emergency Departments using Experience Based Co Design

We would like to invite you to participate in this postgraduate research project, which aims to improve palliative care delivery for older patients, carers and staff in A&E departments. The work stems from evidence that the presentation of patients with palliative care needs in A&E is often a traumatic experience for all involved. Various reasons for this have been proposed including inadequate training and support, lack of resources and the basic factor of a very needy patient group in a fast track environment.

You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

The study is being conducted in two phases. You are invited to participate in phase one.

#### Phase 1

In this first phase data will be gathered from A&E staff, a clinical coder, who takes the patient data collected by the A&E staff and codes it according to standard NHS coding systems, together with observations from a post-take ward round. The data focus on the role of the A&E practitioner, their knowledge, attitudes and experiences of palliative care, and their impact on the journey of the older palliative care patient. The literature does not provide this information. It is important that the researcher has an understanding of A&E staff views and practice with regard to the care of older palliative care patients, together with the coding of these patients and the way they are represented in NHS data, before embarking on the co-design element of the study.

Phase 2 comprises the Experience Based Co-Design study, which uses a qualitative participatory methodology. Using the knowledge gained from Phase 1 the researcher will draw together patients, carers and staff who have had experience of palliative care delivery in A&E. Following a series of filmed interviews to share experiences and identify key areas causing most concern, the participants will work together to design ways to improve the delivery of care.

#### Phase 1: aims and possible benefits

Phase one aims to determine:



- How A&E staff perceive their role, in relation to care of older, palliative patients
- A&E staff experiences of caring for older, palliative patients
- If there is a common understanding amongst A&E staff about the needs of older, palliative patients

▪ **Possible benefits:**

- We expect the findings to improve services in the A&E Department at St Thomas' Hospital for patients and their families and/or carers. Although this may not benefit you personally, information you give may help influence and shape services in the future.

▪ **Recruitment Criteria**

Inclusion criteria:

- Nurses and doctors working full time, part time or as agency staff in St Thomas' Hospital A&E Department.

Exclusion criteria:

- Non-healthcare staff
- Paramedics
- **What will happen if you take part**
- You will have been contacted by either the Practice Development Nurse or Clinical Lead to inform you of this study and give you this information sheet and the consent form below
- Please spend some time reading these forms to decide if you wish to participate
- If you decide to participate, or have any questions, the e-mail address, or contact number you give to the PDN or CL will be passed on to the researcher (Rebecca Blackwell).
- Rebecca will contact you and answer any questions you may have. If you decide to participate she will arrange a time that suits you to conduct the interview.
- Before the interview you will be given two copies of the consent form to sign. One for the research records and one for you to keep.
- Interviews will be conducted on-site at St Thomas' Hospital
- Interviews will be last a maximum of one hour.
- Interviews will be recorded, subject to your permission. Recordings of interviews will be deleted upon transcription and your details anonymised.

▪ **Potential Risks**

The topic in question is an emotive one, which may potentially cause some distress. If this is the case the interview will be stopped until you are ready to continue. If you wish to stop the interview you may, without any blame or pressure to reschedule. Your data collected to that point will also be destroyed if you request this.

In addition to this, senior members of the A&E and Palliative Care Team will be available if you wish to speak to someone further about any issues which arise from the interview.

Due to the nature of the topic it is possible for disclosure of professional misconduct to occur. In this case the researcher will pass this information to the Practice Development Nurse.

▪ **Arrangements for ensuring anonymity and confidentiality**

All data will be handled in accordance with the Data Protection Act (1998). Consent forms (containing identifiable data) will be retained until the completion of this study (2015). All hard copies of identifiable data will be stored in a locked filing cabinet in a secure room at King's College London. Only the Principle Investigator (Rebecca Blackwell, see below for contact details) who will be conducting your interview will have access to this information.

All data will be anonymised by the Principle Investigator prior to analysis and you will not be identified from this stage onwards.

Electronic data is stored on a secure network at King's College London. Any transport of data will be done on an encrypted device.

▪ **Name and contact details of the researcher**  
Rebecca Blackwell. [rebecca.blackwell@kcl.ac.uk](mailto:rebecca.blackwell@kcl.ac.uk)

- It is up to you to decide whether to take part or not. If you decide to take part you are still free to withdraw at any time up to when your data have been transcribed and anonymised (May 2012). You do not need to give reason.
- In addition to withdrawing yourself from the study, you may also withdraw any data/information you have already provided up until it is transcribed for use in the final report.
- If you agree to take part you will be asked whether you would like to be contacted about participation in Phase 2 of this study (which is outlined above? but will be explained to you in more detail at that time). Your participation in this study will not be affected should you choose not to be re-contacted.

If this study has harmed you in any way you can contact King's College London using the details below for further advice and information:

Principle Investigator: Rebecca Blackwell. [rebecca.blackwell@kcl.ac.uk](mailto:rebecca.blackwell@kcl.ac.uk)

James Clerk Maxwell Building, King's College London, 57 Waterloo Road, London

PhD Supervisor: Dr Patricia Grocott. [patricia.grocott@kcl.ac.uk](mailto:patricia.grocott@kcl.ac.uk)

PhD Supervisor: Dr Karen Lowton. [karen.lowton@kcl.ac.uk](mailto:karen.lowton@kcl.ac.uk)

PhD Supervisor: Professor Glenn Robert. [glenn.robert@kcl.ac.uk](mailto:glenn.robert@kcl.ac.uk)

## Appendix 2: Consent form

### CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.



**Title of Study:** Improving the Experiences of Older Palliative Patients, their Carers and Staff in Accident and Emergency Departments using Experience Based Co Design

**King's College Research Ethics Committee Ref:** \_\_\_\_\_

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Please tick  
or initial

- I would like to participate in this study ☐
- I consent to an interview lasting about one hour ☐
- I consent to the interview being audio recorded and transcribed ☐
- I consent to the processing of the information I provide for the purposes of the study ☐
- I understand that such information will be handled in accordance with the terms of the Data Protection Act 1998. ☐
- I understand that if I decide during the research that I no longer wish to participate in this project, I can notify the researchers involved and withdraw immediately without giving any reason. Furthermore, I understand that I will be able to withdraw my data up to the point of data analysis (May 2012). ☐

- I agree to be contacted in the future by King's College London researchers who would like to invite me to participate in follow up studies to this project, or in future studies of a similar nature. ☐
- I consent to the information I contribute being published in an anonymised form and that it will not be possible to identify me from any publications. ☐

**Participant's Statement:**

I \_\_\_\_\_

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

**Signed**

**Date**

**Investigator's Statement:**

I \_\_\_\_\_

Confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the participant.

**Signed**

**Date**

## Appendix 3: Interview topic guide

### Improving the Experiences of Older Palliative Patients, their Carers and Staff in Accident and Emergency Departments using Experience Based Co Design

#### Interview Topic Guide – Participant Group 1: A&E Staff

##### Topic Guide

##### Knowledge

- What training have you had in palliative care provision pre-registration and post?
- What training/education have you had in regards to palliative care provision (or care of the elderly which covers palliative care) in A&E, since working here?

##### Prepared Understanding

- What is your understanding of palliative care
- What is your view of the existing palliative care provision in A&E?
- Do you see palliative care as part of your role?
- If yes, how do you provide it?
- Can you describe how you would assess an older patient who presents in A&E?
- What factors would lead you to categorise an older patient as having palliative care needs?

##### Experiences

- Do you have any memorable experiences of palliative older patients in your department?
- What was good about this experience?
- What was challenging?
- Looking back now, what would you do differently?
- What, if any, effect has this experience had on you (in terms of:
  - Clinical practice
  - Personal/emotional

##### Approach

##### Next Steps

##### From a staff perspective:

- What do you think matters most to palliative patients and their families when they are in A&E?
- What do you think are the needs of an older palliative patient in A&E are?
- How might the provision of palliative care for older people in A&E be improved?

## **Appendix 4: Interview field notes and detail**

### **Interview Field Notes & Detail**

Date	Interview No#	Name	Pseudonym	Gender	Age	Role	A&E Exp
------	------------------	------	-----------	--------	-----	------	---------

Field Notes – General & Participant Specific

Field Notes – Self Reflection

## Appendix 5: Coder information sheet

### INFORMATION SHEET FOR PARTICIPANTS - Coders



REC Reference Number: [PNM/11/12-57](#)

### YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

#### Improving the Experiences of Older Palliative Patients, their Carers and Staff in Accident and Emergency Departments using Experience Based Co Design

We would like to invite you to participate in this postgraduate research project, which aims to improve palliative care delivery for older patients, carers and staff in A&E departments. The work stems from evidence that the presentation of patients with palliative care needs in A&E is often a traumatic experience for all involved. Various reasons for this have been proposed including inadequate training and support, lack of resources and the basic factor of a very needy patient group in a fast track environment.

You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

The study is being conducted in two phases. You are invited to participate in phase one.

#### Phase 1

In this first phase data will be gathered from A&E staff, a clinical coder, together with observations from a post-take ward round. The data focus on the role of the A&E practitioner, their knowledge, attitudes and experiences of palliative care, and their impact on the journey of the older palliative care patient. The literature does not provide this information. It is important that the researcher has an understanding of A&E staff views and practice with regard to the care of older palliative care patients, together with the coding of these patients and the way they are represented in NHS data, before embarking on the co-design element of the study.

Phase 2 comprises the Experience Based Co-Design study, which uses a qualitative participatory methodology. Using the knowledge gained from Phase 1 the researcher will draw together patients, carers and staff who have had experience of palliative care delivery in A&E. Following a series of filmed interviews to share experiences and identify key areas causing most concern, the participants will work together to design ways to improve the delivery of care.

#### Phase 1: aims and possible benefits

Phase one aims to determine:

- How A&E staff perceive their role, in relation to care of older, palliative patients
- A&E staff experiences of caring for older, palliative patients
- If there is a common understanding amongst A&E staff about the needs of older, palliative patients

▪ **Possible benefits:**

We expect the findings to improve services in the A&E Department at St Thomas' Hospital for patients and their families and/or carers. Although this may not benefit you personally, information you give may help influence and shape services in the future.

▪ **Recruitment Criteria**

Inclusion criteria:

- Coders working at St Thomas' Hospital
- **What will happen if you take part**
- You will have been contacted by a consultant working at St Thomas' Trust, informed of this study and been given this information sheet and the consent form below
- Please spend some time reading these forms to decide if you wish to participate
- If you decide to participate, or have any questions, the e-mail address or contact number you give to the consultant will be passed on to the researcher (Rebecca Blackwell).
- Rebecca will contact you and answer any questions you may have. If you decide to participate she will arrange a time that suits you to conduct the interview.
- Before the interview you will be given two copies of the consent form to sign. One for the research records and one for you to keep.
- Interviews will be conducted on-site at St Thomas' Hospital
- Interviews will be last a maximum of one hour.

Interviews will be recorded, subject to your permission. Recordings of interviews will be deleted upon transcription and your details anonymised

▪ **Potential Risks**

N/A

▪ **Arrangements for ensuring anonymity and confidentiality**

- All data will be handled in accordance with the Data Protection Act (1998). Consent forms (containing identifiable data) will be retained until the completion of this study (2015). All hard copies of identifiable data will be stored in a locked filing cabinet in a secure room at King's College London. Only the Principle Investigator (Rebecca Blackwell, see below for contact details) who will be conducting your interview will have access to this information.
- All data will be anonymised by the Principle Investigator prior to analysis and you will not be identified from this stage onwards.
- Electronic data is stored on a secure network at King's College London. Any transport of data will be done on an encrypted device.

▪ **Name and contact details of the researcher**

Rebecca Blackwell. [rebecca.blackwell@kcl.ac.uk](mailto:rebecca.blackwell@kcl.ac.uk)

- It is up to you to decide whether to take part or not. If you decide to take part you are still free to withdraw at any time up to when your data have been transcribed and anonymised (May 2012). You do not need to give reason.
- In addition to withdrawing yourself from the study, you may also withdraw any data/information you have already provided up until it is transcribed for use in the final report.

If this study has harmed you in any way you can contact King's College London using the details below for further advice and information:

Principle Investigator: Rebecca Blackwell. [Rebecca.blackwell@kcl.ac.uk](mailto:Rebecca.blackwell@kcl.ac.uk)



James Clerk Maxwell Building, King's College London, 57 Waterloo Road, London

PhD Supervisor: Dr Patricia Grocott. [Patricia.grocott@kcl.ac.uk](mailto:Patricia.grocott@kcl.ac.uk)

PhD Supervisor: Dr Karen Lowton. [Karen.lowton@kcl.ac.uk](mailto:Karen.lowton@kcl.ac.uk)

PhD Supervisor: Professor Glenn Robert. [Glenn.robert@kcl.ac.uk](mailto:Glenn.robert@kcl.ac.uk)

## Appendix 6: Coder topic guide

### Improving the Experiences of Older Palliative Patients, their Carers and Staff in Accident and Emergency Departments using Experience Based Co Design

#### Interview Topic Guide – Participant Group 2: Coders

##### Introduction

This study aims to improve the experiences of palliative care delivery for older patients, carers and staff in A&E departments. The work stems from evidence that the presentation of patients with palliative care needs in A&E is often a traumatic experience for all involved. Various reasons for this have been proposed including inadequate training and support, lack of resources and the basic factor of a very needy patient group in a fast track environment.

##### Topic Guide

I am really interested in the role of the coder and how they translate the documentation from A&E and recognise palliative care patients. In particular I would like to learn about the processes you have and how you work.

In order to understand these factors better can you please walk me through the process that would lead to an elderly patient admitted to A&E being given a palliative code?

- What is the code for palliative patients?
- What terminology do you look for to give a palliative code?
- At what stage does a patient with a chronic condition receive the palliative code?
- Are there any issues around applying a palliative care code in A&E and other departments?
- How do you ensure consistency in coding by different coders?

Possible scenario to extrapolate more information (if needed):

What of the following factors are the most important to code in a patient with the following factors?  
Would you code this person as palliative?

- Older person
- Homeless
- Known drug user
- Smoker
- Several co-morbidities/health factors (COPD, pancreatic cancer, peripheral vascular disease, septicemia)

## Appendix 7: Feedback sessions information sheet

### Improving the Experiences of Older Palliative Patients, their Carers and Staff in Accident and Emergency Departments using Experience Based Co Design

We would like to invite you to participate in this postgraduate research project, which aims to improve palliative care delivery for older patients, carers and staff in Emergency Departments (ED). The work stems from evidence that the presentation of patients with palliative care needs in the ED is often a traumatic experience for all involved. Various reasons for this have been proposed including inadequate training and support, lack of resources and the basic factor of a very needy patient group in a fast track environment.

You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

The study uses Experience-Based Co-Design; a qualitative participatory methodology. This methodology explores the experiences of those involved in the topic under investigation (in this case, palliative care for older people in the ED). From individual interviews and group workshops, the key areas causing most concern are identified. The stake holders, ED staff, patients, carers and palliative care specialists, then work together to design ways to improve the delivery of care in these areas.

Following a series of interviews with ED staff members exploring their views, experiences, attitudes and understanding of palliative care and older palliative patients who use this department a short series of workshops will be run. The purpose of these workshops is two-fold. First the sessions will present an update of palliative and End-of-Life Care. Secondly to feedback the findings from the interview analysis to a wider group of staff to gain a consensus and agreement on the outcomes and key areas of concern in relation to the care of older palliative patients. The identity of those who participated is protected and they will not be identifiable from any findings presented in this workshop. The workshops will be audio-recorded and transcribed before being submitted to further analysis.

#### **Aims and possible benefit**

##### **Aims:**

- To update ED staff on current work in palliative and End-of Life Care in the Emergency Department
- To feedback early findings from ED staff interviews regarding ED staff experiences, views and attitudes in relation to care of older, palliative patients
- To identify or gain consensus and agreement on the key findings and areas of concern for ED staff about the needs of older, palliative patients

##### **Possible benefit:**

- We expect the findings to improve services in the Emergency Department at St Thomas' Hospital for patients and their families and/or carers. Although this may not benefit you personally, information you give may help influence and shape services in the future.

### Recruitment Criteria

Inclusion criteria:

- Nurses and doctors working full time, part time or as agency staff in St Thomas' Hospital A&E Department.

Exclusion criteria:

- Non-healthcare staff
- Paramedics

### What will happen if you take part?

- The workshops are held as part of a normally scheduled teaching session within working hours
- Please spend some time reading these forms to decide if you wish to participate
- If you decide to participate, have any questions or do not wish to participate you are free to discuss these with the researcher (Rebecca Blackwell) at the start of the session
- Before the workshop you will be given two copies of the consent form to sign. One for the research records and one for you to keep.
- Workshops will be conducted on-site at St Thomas' Hospital
- Workshops will be last a maximum of one hour.
- Workshops will be audio-recorded, subject to your permission. Recordings of interviews will be deleted upon transcription and your details anonymised.

### Potential Risks

The topic in question is an emotive one, which may potentially cause some distress. If you do not wish to participate, or would like to talk to someone following the session senior members of the A&E and Palliative Care Team will be available to discuss any issues which arise from the interview.

Due to the nature of the topic it is possible for disclosure of professional misconduct to occur. In this case the researcher will pass this information to the Practice Development Nurse.

### Arrangements for ensuring anonymity and confidentiality

All data will be handled in accordance with the Data Protection Act (1998). Consent forms (containing identifiable data) will be retained until the completion of this study (2015). All hard copies of identifiable data will be stored in a locked filing cabinet in a secure room at King's College London. Only the Principle Investigator (Rebecca Blackwell, see below for contact details) who will be conducting your interview will have access to this information.

All data will be anonymised by the Principle Investigator prior to analysis and you will not be identified from this stage onwards.

Electronic data is stored on a secure network at King's College London. Any transport of data will be done on an encrypted device.

▪ **Name and contact details of the researcher**

Rebecca Blackwell. [rebecca.blackwell@kcl.ac.uk](mailto:rebecca.blackwell@kcl.ac.uk)

- It is up to you to decide whether to take part or not. If you decide to take part you are still free to withdraw at any time up to when your data have been transcribed and anonymised (December 2012). You do not need to give reason.
- In addition to withdrawing yourself from the study, you may also withdraw any data/information you have already provided up until it is transcribed for use in the final report.
- If you agree to take part you will be asked whether you would like to be contacted about participation in later stages of this study (which are outlined above, but will be explained to you in more detail at that time). Your participation in this study will not be affected should you choose not to be re-contacted.

Principle Investigator: Rebecca Blackwell. [rebecca.blackwell@kcl.ac.uk](mailto:rebecca.blackwell@kcl.ac.uk)

James Clerk Maxwell Building, King's College London, 57 Waterloo Road, London

If this study has harmed you in any way you can contact King's College London using the details below for further advice and information:

PhD Supervisor: Dr Patricia Grocott. [patricia.grocott@kcl.ac.uk](mailto:patricia.grocott@kcl.ac.uk)

PhD Supervisor: Dr Karen Lowton. [karen.lowton@kcl.ac.uk](mailto:karen.lowton@kcl.ac.uk)

PhD Supervisor: Professor Glenn Robert. [glenn.robert@kcl.ac.uk](mailto:glenn.robert@kcl.ac.uk)

## Appendix 8: Feedback consent forms

### CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.



**Title of Study:** Improving the Experiences of Older Palliative Patients, their Carers and Staff in Accident and Emergency Departments using Experience Based Co Design

**King's College Research Ethics Committee Ref:** *REC Reference Number:* PNM/11/12-57

*R&D Reference Number:* **RJ112/N084**

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Please tick  
or initial

- I would like to participate in this study

☐

- I consent to participating in this workshop

☐

- I consent to the workshop being audio recorded and transcribed

☐

- I consent to the processing of the information I provide for the purposes of the study

☐

- I understand that such information will be handled in accordance with the terms of the Data Protection Act 1998.

☐

- I understand that if I decide during the research that I no longer wish to participate in this project, I can notify the researchers involved and withdraw immediately without giving any

☐

reason. Furthermore, I understand that I will be able to withdraw my data up to the point of data analysis (December 2012).

- I agree to be contacted in the future by King's College London researchers who would like to invite me to participate in follow up studies to this project, or in future studies of a similar nature. ☐
- I consent to the information I contribute being published in an anonymised form and that it will not be possible to identify me from any publications. ☐

**Participant's Statement:**

I \_\_\_\_\_

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

**Signed**

**Date**

**Investigator's Statement:**

I \_\_\_\_\_

Confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the participant.

**Signed**

**Date**

## **Appendix 9: Ethics committee amendment approval**

Rebecca Blackwell  
85 Pitfold Road  
Lee  
London  
SE12 9JB

27 February 2012

Dear Rebecca

**PNM/11/12-57 Improving the Experiences of Older Palliative Patients, their Carers and Staff in Accident and Emergency Departments using Experience Based Co Design.**

Review Outcome: Full Approval

Thank you for sending in the amendments/clarifications requested to the above project. I am pleased to inform you that these meet the requirements of the PNM RESC and therefore that full approval is now granted.

Please ensure that you follow all relevant guidance as laid out in the King's College London Guidelines on Good Practice in Academic Research (<http://www.kcl.ac.uk/college/policyzone/index.php?id=247>).

For your information ethical approval is granted until **27 February 2015**. If you need approval beyond this point you will need to apply for an extension to approval at least two weeks prior to this explaining why the extension is needed, (please note however that a full re-application will not be necessary unless the protocol has changed). You should also note that if your approval is for one year, you will not be sent a reminder when it is due to lapse.

Ethical approval is required to cover the duration of the research study, up to the conclusion of the research. The conclusion of the research is defined as the final date or event detailed in the study description section of your approved application form (usually the end of data collection when all work with human participants will have been completed), not the completion of data analysis or publication of the results. For projects that only involve the further analysis of pre-existing data, approval must cover any period during which the researcher will be accessing or evaluating individual sensitive and/or un-anonymised records. Note that after the point at which ethical approval for your study is no longer required due to the study being complete (as per the above definitions), you will still need to ensure all research data/records management and storage procedures agreed to as part of your application are adhered to and carried out accordingly.

If you do not start the project within three months of this letter please contact the Research Ethics Office.



Should you wish to make a modification to the project or request an extension to approval you will need approval for this and should follow the guidance relating to modifying approved applications: <http://www.kcl.ac.uk/innovation/research/support/ethics/applications/modifications.aspx>

The circumstances where modification requests are required include the addition/removal of participant groups, additions/removal/changes to research methods, asking for additional data from participants, extensions to the ethical approval period. Any proposed modifications should only be carried out once full approval for the modification request has been granted.

Any unforeseen ethical problems arising during the course of the project should be reported to the approving committee/panel. In the event of an untoward event or an adverse reaction a full report must be made to the Chair of the approving committee/review panel within one week of the incident.

Please would you also note that we may, for the purposes of audit, contact you from time to time to ascertain the status of your research.

If you have any query about any aspect of this ethical approval, please contact your panel/committee administrator in the first instance

(<http://www.kcl.ac.uk/innovation/research/support/ethics/contact.aspx> ). We wish you every success with this work.

With best wishes

Yours sincerely

Catherine Fieulleateau

Senior Research Ethics Officer

cc: Dr Patricia Grocott

## Appendix 10: Feedback sessions field notes and reflection document

Understanding the palliative care experiences in the Emergency Department for older patients, their carers and staff using Experience-Based Co-Design

Feedback Session # – DATE

### **Field Notes**

### **Points to work on/change**

### **Challenges**

### **Positives**

Summary of Key topics & Issues Raised Teaching Session

Summary of Changes (DATE)	Outcome of Changes (DATE)

## Appendix 11: Feedback sessions ranking sheet

### Improving Palliative Care for Older People in the Emergency Department

**PLEASE ONLY RANK THE TOP THREE** ways in which the provision of care for older patients with palliative care needs and their carers should be improved in the Emergency Department (**with 1 = most importance, 2 = 2<sup>nd</sup> most important, 3 = 3<sup>rd</sup> most important**).

IMPROVEMENT PRIORITIES
(Age) Supporting all staff to view and think about older patients in the ED in the same way as other patients in terms of respecting and responding to their treatment choices and care
(Barriers) Improving awareness of how different professionals (ED staff, palliative care team, staff elsewhere in Trust, community health teams) can work together to provide palliative care for older people in the ED
(Communication & Information) Improving communications between ED staff, specialist palliative care teams and other specialities
(Palliative Care) Improving ED staff understanding - through in service educational sessions - about how Palliative Care is defined, understood and thought about
(Roles) Clarifying the respective roles of patient, carers, ED staff, palliative care teams and community healthcare professionals in providing care to older people with palliative care needs who attend the ED
(Systems and Processes) Making systems and processes in the ED, the wider Trust, and beyond the Trust more efficient and responsive to the needs of older patients with palliative care needs
(Time) Redesigning or reconfiguring ED and other services in ways that would allow more time to care for older patients with palliative care needs who attend the ED
(Training and Education) More formal training and education (in palliative or End of Life Care) during pre & post-registration training of staff

**PLEASE ONLY RANK THE TOP THREE** issues that you think present the biggest barriers **for patients and carers** who have palliative care needs in the ED.

THEME	RANK
Staff attitudes to older patients	
Low awareness amongst staff of available services	
Poor communication between ED and other services	
Poor staff understanding of palliative care	
Poor understanding of different staff roles (including specialist services)	
Inefficient systems and processes	
Lack of staff time to attend to their needs	
Little staff training and education (in palliative or End of Life Care)	

Please use the space below to add any comments you would like to make about the current provision of palliative care to older people and their carers in the ED and how this could be improved:

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---

If you would like to be contacted about the project and attend a meeting with patients to look at service re-design options please provide your e-mail address below:

---

## Appendix 12: Design Principles

### Design Principles for Developing Elderly Care Services in the Emergency Department

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#### Introduction

The following document presents design principles drawn from innovative work at the Geriatric-Emergency Department at Mount Sinai Hospital, New York. Differences in healthcare systems have been considered and the resulting principles are intended as a guide for NHS hospitals developing care of older people in the Emergency Department (ED).

The work at Mount Sinai is led by a multidisciplinary team called ‘Geriatric Emergency Department Innovations in care through Workforce Informatics and Structural Enhancements’ (GEDI WISE). Their aim is to develop a new model to improve care of older people accessing the ED. The ageing population and subsequent healthcare challenges are a global issue. Therefore this project presents an interesting study for the UK as many of our EDs are also starting to develop their own responses. At the time of writing, the US team have not yet published outcomes from their work, however, preliminary findings suggest that this model of care is improving the experience of the ED for patients and carers. Though there are challenges for staff, the majority report improvements in the delivery of care and the impact they can have. Consideration of the principles below could therefore help inform developments in the UK.

#### Design Principles

**Context:** If you are working in an Emergency Department and seeing increasing numbers of older (and palliative) patients...

**Goal:** and you want to improve the experiences of care delivery for older (and palliative) patients, their carers and staff by creating a new model of care...

**Actions:** then it might help if you focus on...

#### **A: COMMUNICATION**

**Establish effective ways, firstly, of communicating with staff at all levels that helps them to understand their respective roles in providing high quality care to these patients and how they relate to each other, and secondly to disseminate information to the department and across the organisation.**

Do this through:

- 1. A dedicated leadership team comprised of individuals from all levels of care provision (including senior management to healthcare assistant and domestic representation) who:**
  - a. Hold regularly scheduled meetings for the leadership team to plan processes and implementation strategies, review and evaluate changes, as well as discussing issues and raising concerns*

- b. Communicate changes with all-level staff via established mechanisms*
- 2. Inclusion of all staff as change agents by:**
  - a. Regularly scheduled meetings or forums for staff groups to communicate changes and new roles, review problems and share successes.*
  - b. Feedback of outcomes of meetings by staff representative to the leadership team*
  - c. Allowing staff to share challenges and concerns and responding via the feedback cycle*
- 3. Strategic use of specialist staff who:**
  - a. Specialise in the care of older people (including older palliative care)*
  - b. Can help review processes and provide training to generalist practitioners*
  - c. Can liaise with patients whose needs are beyond the remit of generalist ED staff*
- 4. Regularly scheduled review of patient needs through**
  - a. Inviting representatives or service users to strategic meetings with the leadership group to share their experience and review processes*
  - b. Staff reporting unmet patient needs*
  - c. Real-time patient & carer feedback*
- 5. Establish formal links with other relevant departments and organisations through :**
  - a. Information dissemination to external services regarding all applicable changes in the department*
  - b. Inviting external groups that link with the ED, for example community and inpatient services, into the department to share and explain changes and strengthen working relationships*
  - c. Working alongside other organisations or groups undertaking similar work to share best practice and learning*
- 6. Clearly defined and consistently used terminology that:**
  - a. Is used as a tool for providing consistency in the care patients and carers can expect from staff*
  - b. Clarifies terms and definitions for more abstract concepts that commonly cause confusion among patients and staff*
  - c. Informs guidelines for communicating processes*
  - d. All staff are trained to use and understand*

## **B: PREPARATION**

**Prepare for a new model of care by identifying core issues and developing targeted responses to meet the needs of the patient population. Using empirical evidence and clinical expertise can help to identify and implement interdisciplinary team roles, pathways and procedures, and help prioritise appropriate training.**

Do this by:

- 1. Drawing together a strong leadership team to:**
  - a. Share input and expertise to review aspects of care delivery that require change*
  - b. Ensure that all-level staff have representation and are included in all relevant processes*
  - c. Plan the dissemination of information; who will oversee this and how will they do it?*
- 2. Review staff and practice to then:**

- a. *Tailor assessment pathways to the needs of the patient group*
  - b. *Provide routine general and specialist geriatric training to staff.*
- 3. Preparing the roles of specialist staff by:**
  - a. *Identifying key specialist roles*
  - b. *Preparing the responsibility of new roles with flexibility to adapt as required*
  - c. *Training them and generalist staff prior to launching the new roles*
  - d. *Ensuring such staff are supported by the leadership team*
- 4. Identifying the biopsychosocial and environmental needs of older (palliative) patients through:**
  - a. *Published evidence, clinical expertise of in-house staff and external specialist practitioners and patient consultation*
  - b. *Consideration of staffing, resources, pathways, physical environment and equipment*
- 5. Creating communication feedback cycles that:**
  - a. *Disseminate information on new processes, changes and roles*
  - b. *Gather feedback on staff regarding changes*
  - c. *Identify additional areas of practice that require attention*
- 6. Realistic planning for the scale of change required**
  - a. *Consider the space, staffing, resource and environmental changes required to meet the needs highlighted above*
  - b. *Link planning to on-going review and development and budget accordingly*
- 7. Prepare for evaluation and review by**
  - a. *Deciding on which outcome measure to record and gather baseline data*
  - b. *Prioritise practice changes so the most important ones are implemented first*
  - c. *Work with IT/statistical support to create a simple data collection system requiring minimal staff input to maintain*

## **C: GOAL ORIENTATED ON-GOING STRATEGIC REVIEW AND DEVELOPMENT**

**Maintain the culture of change enabled by the preparation stage through flexibility, openness to opportunistic action and innovative thinking, supported by leadership, budget and the cyclical feedback systems, which review and respond to patient and staff needs.**

Do this by:

- 1. Maintaining a strong leadership team:**
  - a. *With regular reviews of roles and responsibilities*
  - b. *Provide space and time to share concerns and questions regarding their area of responsibility*
- 2. Prioritising training around:**
  - a. *General care of older people*
  - b. *Specialist aspects such as dementia and end-of-life care*
  - c. *Open space for new needs as they arise*
  - d. *New staff and refresher courses for long-term staff*
- 3. Remaining alert to the needs of older people by:**
  - a. *Monitoring trends for changes in needs*
  - b. *Involving patient representatives and gathering real-time feedback*

- c. *Responding to the different aspects of care of older people which can include numerous specialities*
- 4. Building on relationships with other departments and external services to:**
  - a. *Ensure on-going inclusion of other services in changes in department*
  - b. *Adapt practice to external changes*
  - c. *Maintain joint working to identify best practice across services*
- 5. Continuing to use feedback cycles to:**
  - a. *Review and evaluate changes to pathways, practice and the environment*
  - b. *Identify gaps in staff knowledge and training needs*
  - c. *Highlight new issues or challenges*
  - d. *Give staff a place to voice concerns or feedback successes*



## Appendix 13: Table of Design Principles

	Design Principles	Broad Design Principles
1.	Identify priorities for care of the elderly in the ED and focus your responses appropriately.	<b>Preparation</b> Goal orientated on-going strategic review and development
2.	Consider the funding, space and dedicated staff this scale of change will require to improve the care of the elderly in the ED.	<b>Preparation</b>
3.	Remaining flexible and open can facilitate opportunistic action and innovative thinking within geriatric care in the ED.	Goal orientated on-going strategic review and development
4.	To support on-going strategic review, consider maintaining a dedicated leadership team to oversee all projects, communicating with and supporting all levels of staff (use of cyclical feedback systems).	<b>Communication</b> <b>Preparation</b> Goal orientated on-going strategic review and development
5.	During development of a new model of care for elderly patients in the ED, consider combing scientific evidence with expert opinion and experience.	<b>Preparation</b>
6.	Developing a cyclical system of feedback may enable staff and departmental needs to be effectively monitored, for example what are the needs, have they changed, are interventions proving effective?	<b>Communication</b> <b>Preparation</b> Goal orientated on-going strategic review and development
7.	Retain flexibility for adapting specialist roles, taking account of feedback.	<b>Communication</b> <b>Preparation</b> Goal orientated on-going strategic review and development
8.	Consideration of the physical needs of older patients could help inform design specifications.	<b>Preparation</b>
9.	Develop communication systems within the department as well as across services in order to increase understanding of new roles and responsibilities, for example e-mail or meetings.	<b>Communication</b> Goal orientated on-going strategic review and development
10.	Establish an on-going programme of feedback and review in order to ensure continuous improvement in the care of older people in the ED.	<b>Communication</b> Goal orientated on-going strategic review and development
11.	Defining clear and relevant outcomes at the start of the project may strengthen and focus data collection activities.	<b>Preparation</b>
12.	Prior to starting the project, design a data collection system that requires minimal staff input to simplify outcome measurement activities.	<b>Preparation</b>
13.	Development of a model of care may be enhanced by identifying wider care needs of older patients in the ED.	<b>Communication</b> Goal orientated on-going

		strategic review and development
14.	Systematically consider the following aspects of care delivery: staffing, environment, procedures.	Communication
15.	Consideration of the needs of the patient population could help identify and establish the most appropriate multidisciplinary team.	Goal orientated on-going strategic review and development
16.	Working with other organisations may help identify best practice and establish a minimum data set for benchmarking good shared learning.	Communication Goal orientated on-going strategic review and development
17.	Training and support is still required to ensure the quality of on-going care provision by generalist staff.	Goal orientated on-going strategic review and development
18.	Tailor assessment pathways to the needs of older patients, providing training to staff regarding appropriate use.	Preparation
19.	Identify the knowledge and skill gaps of generalist staff to help tailor the provision of training.	Communication Goal orientated on-going strategic review and development
20.	Identifying, resourcing and integrating specialist practitioner roles could enhance care.	Communication Goal orientated on-going strategic review and development
21.	Consider collaboration between leadership team and specialist practitioners in defining and communicating new roles and responsibilities to the department and organisation.	Communication Goal orientated on-going strategic review and development
22.	If developing an organisational change programme, consider incorporating a cyclical feedback system that encompasses all-level staff input, i.e. physicians, nurses, healthcare assistants, porters, clerks.	Communication Preparation Goal orientated on-going strategic review and development
23.	Care delivery may be aided by clearly defined and consistently used language and terminology.	Communication

## Appendix 14: Critique of Broad Design Principles 2 and 3

### 3

**Broad Design Principle 2 ‘Preparation’** *Facilitate identification of the core issues and develop targeted responses to meet the needs of the patient population. Using empirical evidence and clinical expertise can help to identify and implement interdisciplinary team roles, pathways and procedures, and the appropriate training.*

#### **Design Principles related to the Broad Design Principle ‘Preparation’**

**(DP 1): Identify priorities for care of the elderly in the ED and focus your responses appropriately.**

*(DP 2): Consider the funding, space and dedicated staff this scale of change will require to improve the care of the elderly in the ED.*

**(DP 4): To support on-going strategic review, consider maintaining a dedicated leadership team to oversee all projects, communicating with and supporting all levels of staff (use of cyclical feedback systems).**

*(DP 5): During development of a new model of care for elderly patients in the ED, consider combining scientific evidence with expert opinion and experience.*

**(DP 6): Developing a cyclical system of feedback may enable staff and departmental needs to be effectively monitored, for example what are the needs, have they changed, are interventions proving effective?**

*(DP 7): Retain flexibility for adapting specialist roles, taking account of feedback.*

**(DP 8): Consideration of the physical needs of older patients could help inform design specifications.**

*(DP 11): Defining clear and relevant outcomes at the start of the project may strengthen and focus data collection activities.*

**(DP 12): Prior to starting the project, design a data collection system that requires minimal staff input to simplify outcome measurement activities.**

*(DP 18): Tailor assessment pathways to the needs of older patients, providing training to staff regarding appropriate use*

**(DP 22): If developing an organisational change programme, consider incorporating a cyclical feedback system that encompasses all-level staff input, i.e. physicians, nurses, healthcare assistants, porters, clerks.**

Indicative in the design of the development of this new model of care was a clear understanding of the healthcare challenge (DPs 1 & 2). Pascal et al (2013) state that the initial identification of a design

challenge is key to developing appropriate innovative responses to complex problems. Eleven DPs reflect different aspects of preparation that have enabled or restricted the evolution of the new model of care (Box 3). 'Preparation' refers not only to work that went into the design of the Geriatric-ED, for example; staffing, environment, resources, linking with other services (DPs 2, 8, 18), but also to investment into the system to allow for on-going changes. These include plans to remodel two areas of the Geriatric-ED (DPs 2, 4 & 6), the nurse work station by the open bays (See Photograph 2) and the second is to extend the actual capacity of the Geriatric-ED. The first issue was raised by staff who were concerned that they could not safely see their patients when at the nursing station in the smaller bay area, as it faces the wall. The second issue came from a review of the admission criteria to the Geriatric-ED. More unwell patients, including those with advanced dementia, were still kept in the main ED or resuscitation area. The Geriatric-ED has placed a cap on patient numbers and condition severity to ensure patient and staff safety. At the present time staffing is not sufficient to offer the additional care required by more dependent patients, and there is not a suitable space to care for them. However, the main ED and resuscitation areas remain unsuitable for vulnerable patients who will be competing with more acutely unwell patients for already stretched staff attention and care. Therefore by altering and extending the Geriatric-ED and hiring additional staff, the GEDI WISE team aim to improve the experience and quality of care for older patients in the two ways. Relating to the first issue, the nursing station will be rebuilt to improve visual access to patients and the ward. Regarding the second, additional, unused office space close to the Geriatric-ED will be developed and connected into an observational area for the more vulnerable patients described.

The building blocks of the new department came from a mixture of clinical expertise shared by different practitioners and staff members in the ED and research into geriatric care in other settings (DP 5). These data were pulled together to determine the needs of the patient population, and the responses that would best provide high quality care across all aspects of the ED. The social workers, in particular appeared to be well coordinated, moving between the Geriatric and main ED (DP 7). Bevan et al (2007) state the importance of acknowledging that the outcomes of a new design cannot be known at the early stages. Their advice is to avoid making future plans overly specific. The reflexive way the GEDI WISE team works implies their new model has been designed to expect future changes and to respond to them as they arise (reflected in DPs 4 & 6). Certainly the strong collaborative links to other departments and specialities and the inclusion of innovative programmes such as the CARE Volunteers, suggests a degree in fluidity in the way care is planned and delivered.

However, interviews with members of staff across the Geriatric and main ED and from all multidisciplinary groups indicate there are areas that are not as well developed. One example is staff training. Although there is now a rolling training programme for providing geriatric care, it started some way into the project and is at a basic level, challenging common misconceptions regarding older

people and their biopsychosocial needs. The GEDI WISE team are working to provide high quality care but they may need to provide more tailored and advanced training (DPs 6, 18 & 22).

Another area that appeared challenging pertained to measuring outcomes. DPs 11 and 12 evolved specifically from observations of the GEDI WISE team grappling with this issue. Identifying and sharing relevant core data from the three hospital sites engaged in the grant programme appeared complicated and was raised in the majority of GEDI WISE team meetings observed. Part of the challenge appeared to stem from the way in which the project has evolved. The Geriatric-ED was created out of an opportunity and available funds, but without an established team – the GEDI WISE team was developed after the initial plans for the physical environment were underway. This meant that certain decisions and plans that ideally would have been made prior to the opening of the department, by necessity are being made while the work is in situ. Specifically, which outcomes are measured and how the data is stored and analysed.

### **Broad Design Principle 3 ‘Goal orientated on-going strategic review and development’:**

*Maintain a culture of change through flexibility, openness to opportunistic action and innovative thinking, supported by leadership, budget and the cyclical feedback systems, which review and respond to patient and staff needs.*

#### **Design Principles related to the Broad Design Principle ‘Goal orientated on-going strategic review and development’**

**(DP 1): Identify priorities for care of the elderly in the ED and focus your responses appropriately.**

*(DP 3): Remaining flexible and open can facilitate opportunistic action and innovative thinking within geriatric care in the ED.*

**(DP 4): To support on-going strategic review, consider maintaining a dedicated leadership team to oversee all projects, communicating with and supporting all levels of staff (use of cyclical feedback systems).**

*(DP 6): Developing a cyclical system of feedback may enable staff and departmental needs to be effectively monitored, for example what are the needs, have they changed, are interventions proving effective?*

**(DP 7): Retain flexibility for adapting specialist roles, taking account of feedback.**

*(DP 9): Develop communication systems within the department as well as across services in order to increase understanding of new roles and responsibilities, for example e-mail or meetings.*

**(DP 10): Establish an on-going programme of feedback and review in order to ensure**

**continuous improvement in the care of older people in the ED.**

*(DP 13): Development of a model of care may be enhanced by identifying wider care needs of older patients in the ED.*

**(DP 15): Consideration of the needs of the patient population could help identify and establish the most appropriate multidisciplinary team.**

*(DP 16): Working with other organisations may help identify best practice and establish a minimum data set for benchmarking good shared learning.*

**(DP 17): Training and support is still required to ensure the quality of on-going care provision by generalist staff.**

*(DP 19): Identify knowledge and skill gaps of generalist ED staff in order to provide tailored training.*

**(DP 20): Identifying, resourcing and integrating specialist practitioner roles could enhance care.**

*(DP 21): Consider collaboration between leadership team and specialist practitioners in defining and communicating new roles and responsibilities to the department and organisation.*

**(DP 22): If developing an organisational change programme, consider incorporating a cyclical feedback system that encompasses all-level staff input, i.e. physicians, nurses, healthcare assistants, porters, clerks.**

The goals at Mount Sinai ED extend beyond simply providing a new space for older people. The focus was on maintaining a culture of improvement in the quality of care through change and innovative practice in all areas (DPs 1, 3, 6, 9, 10, 16, 17, 22). Fifteen DPs emerged from the data pertaining to aspects of developing an evolving model of care (Box 4). Regular review of various innovations was observed from the structure of working of the GEDI WISE team (reflected in DPs 10 & 22). The team is comprised of key leadership and specialist practitioners who meet on a regular basis (DPs 4, 10, 15 & 21). Observation of their meetings revealed the passion and dedication of all staff members to improve care of the patients. However, there were challenges within the group. Perhaps in part due to the large mix of practitioners, each with their own agenda, during some meetings the focus would get lost in a discussion between a sub-section of the group (DP 1). This challenge is also reported in a case study by Romme & Damen (2007) in which participants reported a similar issue where design meetings became laborious, veering from the point and focusing on the minutia of finer points. The GEDI WISE team meetings were also used to share any issues from practice, including concerns from junior staff members (DP 22). Looking at the comments and quotes from junior staff members it appears that there is a division in opinion about, and experience of, the Geriatric ED. A particularly division lies between the night and day staff, already highlighted in BDP 1. Day staff have access to more resources and are easier to include in updates and practice changes from key staff member change agents. Most healthcare services finish between 5-7pm and there are fewer staff available on a night shift. This sort of staff-inclusion issue is common in organisational

redesign, and one management suggestion is the use of a circular process of redesign, with aspects of leadership, design and measurement occurring at both management and ground staff levels (Romme and Damen 2007). The pivotal factor is to identify a spokesperson from each group who will liaise between main design team and their own staff group. This supports sustainable circular organisational development by facilitating informed consent from all staff in the process, and highlights integral education needs (DPs 4, 6, 9, 10 & 17).

Other DPs reflect the impact of new specialist roles in the Geriatric ED in creating new ways of working (DPs 9, 15, 19 & 20). These roles were resourced based on findings from the literature, but the staff operate with freedom to adapt and develop the roles and responsibilities according to the needs of the patients and staff (DP 7). This type of flexibility can also be found in the departmental research. Of concern to some practitioners are the increasing numbers of older patient with palliative and end-of-life needs who are accessing the ED. In response, research, led by a member of GEDI WISE, is underway to determine triggers and care needs of these patients. The role of the Geriatric ED will expand according to the research findings to facilitate efficient and appropriate care (DP 13). Within these changes identification of staff knowledge and skill is vital to ensuring consistent care delivery (DP 19). Interview data focusing on palliative care revealed that the considerable variation in staff understanding of what palliative actually is, as well as its provision by staff. One possible response is to tailor education and training accordingly (DPs 17 & 19).

While the first two BDPs, Communication and Preparation, stand alone as key factors used to develop a new model of care at Mount Sinai, they also feed into this final one; Goal orientated on-going strategic review and development. Facets of communication and preparation have been used by the GEDI WISE team to support and maintain goal orientated on-going strategic review and developments. Thus the analysis concludes that the three BDPs have served as building blocks for a model of care that continues to evolve with the needs of the patients and carers.

## Appendix 15: Conference Poster

# GEDI WISE: Fieldwork Informing an Experience-Based Co-Design Study of Palliative Care for Older People in the Emergency Department in the UK

### Aim

To observe practice the GEDI WISE Team at the Geriatric-only Emergency Department (ED) at Mount Sinai Hospital, New York.

To extrapolate principles for the UK as part of an Experience-Based Co-Design study aiming to improve ED experiences for older patients, their carers and staff.

### Background

Increasing numbers of older people with long-term conditions, cancers and co-morbidities are putting pressure on EDs. Use may be triggered by disease exacerbation, progression, patient/carer anxiety, or unavailability of other services; in this context ED interactions can be distressing for all involved. In the US, innovative responses to this problem include Geriatric-Only Emergency Rooms.

### Methods

Qualitative data collection conducted within the main ED and the Geriatric-ED (a separate room, designed and operating differently to the main ED) over one month. Data collected as field notes from observation and informational interviews with patients, carers, staff, researchers, and staff training sessions.

### Results

Thematic data analysis led to the development of three Broad Design Principles unpinning a new model of care: Communication, Preparation and Goal orientated strategic review and development.



For more information about Mount Sinai's geriatric emergency department, scan here or go to: [goo.gl/MNjyG](https://goo.gl/MNjyG)



### Conclusion and On-going Work

The three Broad Design Principles will be used to inform and support redesign focus groups at a later stage of the study. The focus groups will be comprised of ED staff, older palliative patients and their carers.

### Practical examples within the three Broad Design Principles

#### 1. Communication

Confusion and delirium are exacerbated in the ED. Volunteers identify at-risk patients and engage them in conversation, providing distraction tools such as stress balls and brain training games.

#### 2. Preparation

The layout, design and equipment in the Geriatric-ED was geared to the needs of older patients. Special features include diurnal skylights (see photograph) and provision of hearing aids and reading glasses.

#### 3. Goal orientated on-going strategic review & development

ED staff have identified further needs of older patients who are using the Geriatric-ED, e.g. palliative and End-of-Life care needs. Research is underway to determine how the department can expand to provide appropriate care.

Lead Author Contact: [rebecca.blackwell@kcl.ac.uk](mailto:rebecca.blackwell@kcl.ac.uk)

Authors: **R. Blackwell**, Florence Nightingale School of Nursing and Midwifery, King's College London, London, United Kingdom; Emergency Department, Guy's and St Thomas' Hospital NHS Foundation Trust, London, United Kingdom

**C. Grudzen, K. Baumlín, L. Richardson, U. Hwang, T. GEDI WISE Investigators**, Emergency Medicine, Icahn School of Medicine, Mount Sinai, New York, New York, United States.

Fieldtrip funded by a Florence Nightingale Foundation Travel Scholarship within a wider doctoral study.

GEDI WISE was supported by Grant Number 1C1CMS331055-01 from the Department of Health & Human Services, Centers for Medicare & Medicaid Services as part of a larger initiative to explore innovations in health care payment and service delivery that might improve quality and lower costs.

The contents are solely the responsibility of the authors and have not been approved by the Department of Health and Human Services, Centers for Medicare & Medicaid Services.



## Appendix 16: information sheet

### INFORMATION SHEET FOR PARTICIPANTS

*REC Reference Number: 14/LO/0136*

#### **Improving the experiences of palliative care in the Emergency Department for older people, their carers and staff using Experience-based Co-design**

We would like to invite you to participate in this postgraduate research project, funded by a King's College London Health Schools Postgraduate Studentship in collaboration with Guy's and St Thomas' NHS Foundation Trust. **You should only participate if you want to; choosing not to take part will not disadvantage you in any way.** Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

**NB: palliative care can be given to someone with an incurable, often long-term, life-limiting condition, for example, chronic obstructive pulmonary disease (COPD), heart failure, cancer or neurological disease such as Parkinson's. Palliative care looks to offer total support (medical, social, psychological and spiritual) to patients and their families.**

#### **What is the purpose of this research?**

The purpose of this research is to explore and improve experiences of palliative care delivery for older people with palliative care needs, their carers (family members) and staff in Accident & Emergency (A&E) departments. The study aims to understand the needs of patients, carers and staff to identify where there may be difficulties. You are invited to share your experiences and then work alongside other patients, carers and emergency staff to use your shared experiences to redesign the service and improve palliative care delivery at St Thomas' Hospital A&E.

#### **Why is this research being done?**

This project comes from evidence that the use of the A&E by older people with palliative care needs can often be a distressing experience for all involved. As the A&E was not originally designed to meet the type of needs that these patients have, it can be very difficult for staff to provide the best care for them.

This research aims to explore the experiences of the patients, carers and staff in order to identify ways to improve the service and experience for all involved.

### **Why have I been chosen (inclusion criteria)?**

This project focuses on the experience of A&E staff, older people with palliative care needs and their carers who have used St Thomas' Hospital Accident and Emergency Department. As a patient at this hospital, aged 65 or older with a long-term condition or a carer (family member or informal carer) of a person aged 65 or older who has used the A&E you are ideally placed to tell us how to improve the patient and carer experience of this service.

### **What will happen if I agree to take part?**

You are invited to take part in the study which is being conducted in three phases over the course of one year (see below). You have the option to take part in all three phases, or in phases 1 and 2, or solely in phase 3.

#### **Phase 1: An interview about your experience by the lead researcher, Rebecca Blackwell**

During the interviews you will be asked to tell your story of being a patient or carer in A&E. With your permission this interview will be audio recorded and filmed. We ask permission to film the interviews as this is a powerful method of identifying issues and sharing experiences. Recordings of interviews will be transcribed and then the audio recording will be deleted.

#### **Phase 2: Viewing your film**

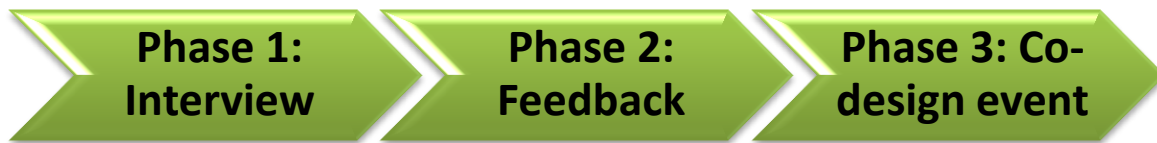
The filmed interview will be returned to you so you can view it and decide whether to agree to parts of the film being shared with other patients and staff. You will be given a release and consent form to sign specifically relating to the use of this data.

You will also be asked to fill in a short form based on the information given from the patient and carer interviews, asking you to identify the main areas you feel are a priority for improving palliative care in the A&E.

#### **Phase 3: Attending a co-design event**

In Phase 3 a workshop, known as co-design event, will be held. Patients, carers, staff and any other care groups or services that link with A&E will be invited to attend. The aim of this session is to work together in groups to design better patient and staff experiences. A short DVD made of a collection of key moments from different patients and carers, as agreed upon in Phase 2, along with information collected from staff interviews will be used to help with this process. Notes will be made documenting the event, and photographs will be taken to be used in dissemination activities such as presentations, as well as the final thesis for this study. If you do not wish to be in photographs, you will be given a

red sticker to put on your name badge. If you are willing to be in photographs you will be given a blue sticker.



### **What are the possible disadvantages of taking part?**

The interview will take about 60 minutes and will be held in a venue that is convenient for you. You will be asked to share your story of being in the A&E. The questions should not be upsetting for you but if you are free to stop the interview at point if you wish to. With your permission, your GP will be notified about your participation in the study and will be available if you need to discuss any issues raised in the interview, or be referred for additional support to your hospital consultant.

### **Possible benefits**

The findings are expected improve services in the A&E Department at St Thomas' Hospital for patients and their families and/or carers. Although this may not benefit you personally, the information you give may help influence and shape services in the future.

### **What information will be held about me?**

We will follow ethical and legal practice and all information about you will be handled in confidence as per the UK Data Protection Act 1998. The data collected for the study will be analysed to learn more about the experiences of patients and carers with palliative care needs in A&E.

To ensure your confidentiality is maintained only the research team will have access to identifiable information that you provide. The audio recorded interviews will be coded using numbers and will not show your name before they are sent to an external service for transcription. The audio tapes of the interview will be destroyed once they have been transcribed and analysed. They will be kept in a locked file in a locked room at King's College London.

A short DVD will be made from the filmed interviews. This will include short segments from the patient and carer interviews. No information on your condition, name or location will be on the DVD. The DVD will be kept – with your permission – to be used as an education tool for healthcare professionals working in A&E.

To protect your confidentiality, your name, condition and personal details will not be shared in the thesis of this project and any subsequent publications, and you will not be identifiable from any quotes used from your interview.

The **principle investigator**, Rebecca Blackwell, will be responsible for security and access to the data. At the end of the study, any information you provided will be secured for seven years in keeping with standard research practice, before being destroyed as confidential waste

### **What will happen to the results of the research study?**

The results will be shared with healthcare staff as part of service improvement work at St Thomas' A&E. The study will be written up in the PhD thesis of this study, published in professional journals and presented at healthcare conferences. The results may be shared online as part of on-going service improvement work and may also include international service improvement work.

### **FAQs**

#### **1) Do I have to take part?**

No. It is up to you to decide whether to take part or not. If you decide to take part you are free to withdraw from the study at any time and without giving a reason.

#### **2) If I change my mind about being the study can I withdraw my information and data?**

You can withdraw your data up to the end of Phase 2 when the DVD will be made (July 2014). However you can withdraw your active participation in the study at any stage without giving a reason.

#### **3) Will I be contacted about future studies?**

If you agree to take part you will be asked whether you are happy to be contacted about participation in future studies. You are free to decline. Your participation in this study will not be affected should you choose not to be re-contacted.

#### **4) What will happen next?**

If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. The researcher will then contact you to arrange a time and place convenient to you, to carry out the interview.

If you have any questions or require more information about this study, please contact the researcher using the following contact details:

Rebecca Blackwell. [rebecca.blackwell@kcl.ac.uk](mailto:rebecca.blackwell@kcl.ac.uk)

### **Complaints or Concerns**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions **Chief Investigator Dr Patricia Grocott**

([patricia.grocott@kcl.ac.uk](mailto:patricia.grocott@kcl.ac.uk)) **Principle Investigator Rebecca Blackwell**

([rebecca.blackwell@kcl.ac.uk](mailto:rebecca.blackwell@kcl.ac.uk)). If you remain unhappy and wish to complain formally, you can:

- Telephone the complaints department on 020 7188 3514
- E-mail your complaint to [Complaints2@gstt.nhs.uk](mailto:Complaints2@gstt.nhs.uk)
- Write to the Chief Executive, Ron Kerr at the address below
- Write to the complaints department at the address below

Guy's and St Thomas' NHS Foundation Trust  
Guy's Hospital  
Great Maze Pond  
London SE1 9RT

## Appendix 17: consent form



King's College London  
James Clerk Maxwell Building  
57 Waterloo Road  
London SE1 8WA

Centre Number:

Study Number: 14/LO/0136

Patient Identification Number for this trial:

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### CONSENT FORM

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Title of Project: **Improving the experiences of palliative care in the Emergency Department for older people, their carers and staff using Experience-based Co-design**

Name of Researcher: **Rebecca Blackwell**

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 02/01/2014 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. Furthermore, I understand that I will be able to withdraw my data up to the point of the making of the DVD. ☐
3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from King's College London, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I agree to my GP being informed of my participation in the study. ☐
5. I agree to participate in Phase 1 (an audio interview about my experiences in A&E). ☐
6. I agree for my interview to be video-recorded. ☐

7. I agree to review the film of my interview for Phase 2.

☐

8. I am aware that if I agree to parts of my filmed interview being used I will be expected to sign a release form. The release form gives permission for my interview to be used in different formats such as video, paper and/or electronic to share with others. This will include other carers and health professionals for the purposes of this research and for educational and service improvement purposes in the future, in the UK and abroad. It may include online use.

☐

9. I am happy to be contacted by the researchers regarding future work on this topic.

☐

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Person	Date	Signature

taking consent.

## Appendix 18: Data release form

### RELEASE AND CONSENT FORM FOR RIGHT TO PARTICIPANT'S FILMED INTERVIEW DATA

**Ethics Number: 14/LO/0136**

**Improving the experiences of palliative care in the Emergency Department for older people,  
their carers and staff using Experience-based Co-design**

Thank you for your participation in this study. Please sign this form to confirm your agreement to the following:

I agree to the inclusion of my filmed interview in this DVD, the nature of which has been explained to me. I understand that my biographical details (name, contact details, identifiable information) will be kept confidential but my image and interview comments may be used in an edited form. I agree that King's College London holds the full rights to the footage of my contribution.

I understand that this DVD and my interview data may be used in different mediums in health education and organisational design work around the world.

Read, understood and agreed by:

.....

(Participant name)

(Participant signature)

(Date)



## **Appendix 19: Letter of support from clinical lead**

### **Letter of Support from Guy's and St Thomas' NHS Foundation Trust Accident and Emergency Department**

**Research Ethics Reference: 14/LO/0136**

The study '*Improving palliative care experiences in the Emergency with older patients, carers and staff using Experience-based Co-design*' is being conducted under the supervision and support of St Thomas' Hospital Accident and Emergency Department.

You do not have to take part in the study and your involvement is entirely voluntary. If you agree to take part, all information collected about you and your experiences during the interview will be kept strictly confidential, and only shared with other patients and staff if you have given your signed consent.

The information sheet explains that, with your permission, we would like to audio record and film you talking about your experiences. The film will be returned to you so that you can view it and decide whether to agree to parts of the film being shared with other patients and staff.

A decision to not take part, or to take part and agree to your experiences being shared will not influence in any way the standard of care or treatment you receive from Guy's and St Thomas' NHS Foundation Trust.

Signed

Dr Katherine Henderson

Lead Clinical Consultant, St Thomas' Accident and Emergency Department

## **Appendix 20: Inclusion/exclusion sheet for staff**

### **Improving experiences of palliative care in the Emergency Department for older patients, carers and staff using Experience-based Co-design**

#### **Study Recruitment Criteria (to be given to staff)**

##### **Patient inclusion criteria**

- Age 65+
- English speaking
- Patient at St Thomas' Hospital Emergency Department
- Living in Lambeth or Southwark
- Patients with long term/terminal conditions (adapted from Beynon et al 2011)
  - Palliative condition definition: Cancer, chronic obstructive pulmonary disease (COPD), heart failure, renal failure, liver failure, neurological disease (multiple sclerosis, Parkinson's, motor neuron disease) AND symptoms (pain, breathlessness, nausea, weight loss, anxiety) and/or complex social needs

##### **Patient Exclusion Criteria**

- Non-English speaking
- A patient aged 64 or younger
- A cognitive impairment that will prevent informed consent, e.g. dementia
- Expected to be within the final two months of life as per the AMBER care pathway guidance

##### **Carer inclusion criteria**

- English speaking
- Living in Lambeth or Southwark
- Carer (family member, close friend, main contact) of a palliative patient aged 65+ who has used St Thomas' Hospital Emergency Department

## Appendix 21: GP information letter

Florence Nightingale School of Nursing & Midwifery  
King's College London  
James Clerk Maxwell Building  
57 Waterloo Road  
London SE1 8WA  
[rebecca.blackwell@kcl.ac.uk](mailto:rebecca.blackwell@kcl.ac.uk)

DATE

Dear

This letter is to inform you that \_\_\_\_\_ will be participating in the study 'Improving the experiences of palliative care in the Emergency Department for older people, their carers and staff using Experience-based Co-design' (Rec Ref: REC Ref: 14/LO/0136) based on their experience as a patient at St Thomas' Hospital Emergency Department (ED). This is a qualitative participatory action research study to explore and improve experiences of palliative care in the ED.

This work is being undertaken at, and in collaboration with Guy's and St Thomas' NHS Foundation Trust as part of a post-graduate study from King's College London.

Enclosed are the information and consent forms that \_\_\_\_\_ received from the research team at King's College London. These should answer any questions you may have but please contact the research team if you have any further queries about the project.

This work will be commencing from January 2014 until January 2015, during which time the Principle Investigator will visit \_\_\_\_\_ in a location selected by the participant. With their permission an audio recorded and filmed interview about their experiences of the ED will be conducted. Following analysis of the data, \_\_\_\_\_ will receive a copy of their film and be asked for permission to use it as part of a short DVD presenting the main issues for delivery of palliative care in the ED. If they agree to continue their participation, they will be invited to attend co-design workshops with other patients, carers and ED staff to work together to design service improvements.

The process should not cause distress but in case any issues are raised that need further clinical support, we are advising \_\_\_\_\_ to contact you for further help and referrals.

If you wish to discuss this with us please contact us on the e-mail address given above.

Yours sincerely

Rebecca Blackwell

PhD Supervisors:

Dr Patrica Grocott [patricia.grocott@kcl.ac.uk](mailto:patricia.grocott@kcl.ac.uk)

Dr Karen Lowton [karen.lowton@kcl.ac.uk](mailto:karen.lowton@kcl.ac.uk)

Professor Glenn Robert [glenn.robert@kcl.ac.uk](mailto:glenn.robert@kcl.ac.uk)

Clinical Advisor:

Dr Katherine Henderson [Katherine.Henderson@gstt.nhs.uk](mailto:Katherine.Henderson@gstt.nhs.uk)

## Appendix 22: Transcript: Ann's Story

SOUND TRANSCRIPTION FOR: Rebecca Blackwell

INTERVIEW WITH: C1

FILE NUMBER: 1 of 2

TRANSCRIPTION DATE: 15.09.14

REQUESTED BY: REBECCA BLACKWELL

0:00:27

Int. Okay, so to start can you just tell me what happened that led up to and your husband needing to go into the Emergency Department at St. Thomas's.

0:00:37

C1. Yes. Uh, uh Alan was diagnosed with uh lung cancer at the, um December of 2010 um that in itself was such a shock uh as he never smoked uh ever, um was a fit man, loved to jog, to play football, to play cricket, so was a sporting man so this was an absolute real shock and we started uh chemotherapy at Charr, uh at, at the hospital in Charing Cross in the January of 2011 and uh Alan's reaction to, to the chemotherapy was uh positive, in fact his cough got better, his breathing got better so it was quite an enriching time to think you were actually going to have treatment that could work. Now I'm a nurse by background and so my knowledge of the, of the diagnosis was of course never one that uh I could feel really positive about the future about, but we, **we had information about neutropenia and how to watch for, for this condition and if this was to happen we should go to the nearest A&E.** Well our nearest A&E is literally down the road at, at St. Thomas's so **I felt very confident that that would be um a good place uh to go uh never thinking that, that we'd have to go there and uh the shock of that first time of, of seeing Alan deteriorate before my very eyes, taking the temperature as instructed and realising then that um I had to follow instructions.** So the very first time um it was just a bit of a, maybe hiccup and uh everything would be sorted and of course when we got to A&E uh it wasn't, it wasn't really like that at all. Uh **people as always are very kind, very professional** uh Alan wasn't as afraid cos it was the fir, first experience and **I think he didn't really understand the potential seriousness of what was happening** and I gave him some more information but gave it him uh as he had said to me always sound very confident so he didn't feel concerned. I think the first time it, it

was so difficult because **the first questions are, well what's wrong, can you tell me what's wrong, and so he'd say well I've diagnosed with lung cancer, oh, oh right, so you, you, you, why are you here then, and oh so then I would interrupt and say uh well we've been told to come because of Alan's temperature and the infection and, and uh, uh his immune system and so that's why we're here, and I would then say I'm a nurse actually as well and so I, I understand uh why we've got to be here and then you, the history got taken, have you had any illnesses before, and we went through this, the, the whole procedure of um, sorry what did you say?**

0:03:53

Int. So sorry, I'm just looking cos I need to move the wire cos it keeps um bashing on your hand and it's .....sorry it was. It's okay.

(Chitchat)

0:04:25

Int. Um if you come back in from um when you say that they were taking the history. Sorry to.

C1. That's okay, that's okay.

Int. Um, I mean I'll, I'll lead, lead you in.

C1. Okay, thank you.

0:04:37

C1. So obviously um the med, medical staff and the nursing staff needed a history taken and what uh made it more confusing was **there was no access uh to Alan's case files because it wasn't the same Trust** and it was almost well why haven't you, why didn't you go to Charing Cross's A&E, because I asked that and they said the time it would take at the hour, because of course it always happens, and it continued to happen at the most inconvenient time if there is ever a, a better time, of London traffic and how was I going to get him there, whereas he was feeling so unwell that A&E was suitable and, and I did ring beforehand and they said well yes you must bring him here. Um I, I again think to myself we then went through that history taking on 2 occasions um within half an hour because another doctor came along and started to ask the same questions and I then met a nurse who I knew who said oh Ann, I'm so sorry, um I can't move Alan anywhere else, there isn't anywhere, as soon as there is we'll see if we can get a, a, a quieter part of A&E. And of course we understand that and um I understood it totally, and the last person to ever complain would be Alan, and so we, we didn't realise at the time that maybe this could be done differently, I certainly didn't realise that. But as that occasion happened regularly after the chemotherapy it would be me taking the temperature, I would go into the bathroom, I would get Alan's toilet bag ready and brace myself literally to tell him we've got to go Alan, we've got to go over to A&E and he would go oh no, not because of the staff, not even because what they were going to do with him because they were going to help him to, to make sure he got his next chemotherapy, but it was the ordeal and the ordeal was dreadful and I think as you, as we got more into the uh treatment and the reality of what was really happening my fear was that something would happen to him in the A&E and he would die there uh or he'd die on the way or into the ward and I think I was wanting to say look I know what it is, could you just please take him somewhere where this can happen and not here, and it's of course you wait for, **you wait for the bloods to come back, you wait for the porter, you wait for, and it could be done differently** and that's why I'm so pleased to be part of, of this research because in a way anything that helps professionals like myself, nurses, understand that we could do it differently and it would make such a huge difference I want to be part of that.

0:07:52

Int. When you say, could be done differently, what do you have in mind, what, what would you do diff, what would have them do differently if you could do it again?

0:08:01

C1. Well, nobody asked us anything about our thoughts, about the, what, how do we want the treatment, where do we want the treatment to take place, uh, uh we, we knew that going in for chemotherapy, which was, which is really quite easy, the, the chemotherapy days, um and they never made Alan ill ex, with the exception of the neutropenia of course which is, is life threatening, but I think the reality is that we can't have a separate room for every condition and we know what an A&E is, it's an accident and an emergency, yes Alan's an emergency but he's, he, he was a, an oncology emergency and the oncology department closes at 6 where the chemotherapy is given and so the only way you can access to be, have treatment is through the A&E and therefore we have to totally rethink um the admission process and not only the admission process but could we have had something with us that I could have had a plan with me in some way. Um I, I had a card that said how much chemotherapy he'd had and what he'd had um and, and that was all really and I, I would have liked to have had something else so whenever we visited Outpatients to have bloods tested, um to see if Alan could have chemotherapy, the next round, you would get a copy now, um patient has a copy, so I started to collect all of those and whenever we went in I took those all in with me to give them at least some background, which of course they needed uh and then we decided um that it was really, we'd, we'd changed, we changed them to Guys & St. Thomas's so they could have access to the records where Alan's first referral was by Imperial and so that's why we were in Charing Cross, and of course he'd built a relationship with that consultant and so wanted to stay um even though going to a different A&E was, it wasn't inconvenient time-wise but it was because there were no safety-wise I suppose there were not the notes until we took a decision to transfer and, and you see even then it, it didn't make any difference, yes you could access the notes but you don't go to Guys um in the middle of the night, you go to, you go to A&E, and, and that's, that's the difficulty. I also did notice because as nurses do uh I saw a nurse and a carer which was hard um but they didn't really, they knew we were in the wrong place, they, they knew that and so we were very quiet and I just stayed by Alan and kept reassuring him that the, we will be transferred to and everything's gonna be okay, so I was able to do that. I think if there had not been anybody with Alan I'm not sure how that goes, only that must be so terrifying for the person, for the patient. Um was it more terrifying for me that I knew, possibly, um although to be afraid with no knowledge and, and no understanding of please could you do this in a different way uh but what about people who get admitted and don't have anybody with them. And the thing I felt fortunate that I'd had my training to at least fill in the gaps with Alan, that other staff couldn't because they were far, I mean it was, nobody was just sitting around, everybody was extremely busy.

0:12:04

Int. Uh, when you say gaps, what, what gaps were they not filling in, or not able to fill in that you did?

0:12:12

C1. Well I suppose we, we would, it, we would use many words for it but it was um we were not in, kept informed, it, uh but what was there, there wasn't anything to inform us really, you see you don't go in as a stretcher case so we walked in, I got a taxi, we

walked in and this is really worth saying, when you go in and you sit in the walk-in part of A&E the world is in there with all sorts of things. I am very aware that Alan is neutropenic and I sit him down there and I try to explain to the receptionist that this is an emergency and um I even had the card with me to show this, but of course again um all the receptionist can do is, is take details, have you been here before. I can see Alan sitting where he's sitting and it's just, it's not the right place, so in fairness uh we hardly ever waited more than 20 minutes to, to, to go into the main part but even that felt, you see he felt weary, he looked, he looked totally weary because I knew I had to get him there, I knew I, I couldn't drive him there, uh so a taxi, and we were able to do that uh and of course that made life very easy to just get out of the taxi and walk in to A&E, but I don't, I think the whole process of other people that I've read about or I've heard them mention is waiting for the ambulance to come, that whole procedure of get, of going to hospital in the ambulance with a relative and then knowing that there's going to be a wait and, and you know how urgent the care is and that's the gap because there was nobody to talk to us about how we felt. Um, uh, nobody to talk to us about, you know we were obviously afraid, and I tried very hard not to be, and to say well oh that's, oh I know that nurse, and gosh that's good, and this seems to be happening now and well it's all okay, but Al, Alan was weary, we had a very very sick man who, who was terminal and he's lying on a trolley in A&E and there, there must be a different route for this and there, there must be an area where they sit people who are requiring palliative care in all its format um and, and the staff were not able to provide that cos they were not there necessarily to provide that.

0:15:14

Int. Can you tell me a bit more about that type of care that you have told me you needed?

0:15:22

C1. Well we had palliative care um from um the Professor uh George, uh was, was just amazing and, and his team so they would visit us at home and whenever we would get to a ward I would say Alan wants to have his treatment and care for, at home, um but uh I'd have liked to have had something to have taken in with me to that effect and uh and that didn't, that didn't happen. In fact we didn't have palliative care um until it got so, more, more complicated and that, that was a nurse in, in St. Thomas's that suggested we should meet that team. Um a, again then of course the reality of what is going to happen hits, kicks in but with skilled people who were helping us with the conversation, very much helping us with the conversation and helping me um and supporting me uh knowing uh that I was Alan's nurse but also knowing that I was Alan's wife and, and that was, that was very obvious and so that palliative care team had the expertise which A&E staff well can have, uh could have, but, but really didn't appear to have um and that was obvious because we could, we could all see and hear um what everybody was dealing with and doing. So you actually also felt well you know I'm, I suppose I, well I'm not bleeding or I, I haven't got chest pain or I haven't this and so that's the, that's the awkwardness of a, a cancer patient with neutropenia is that you, you do say now you must be careful where you go, you mustn't mix with a lot of people with children, with pets and all of that but when, when it's really serious you can sit in out, you know Outpatient of A&E and, and wait and that doesn't make sense to me. Talking, talking to us um I, I knew they cared, there was no doubt, doubt in my mind about that but we were left long, long periods of time but at least he wasn't alone. The, and then um my, my son would come cos I would say your dad's, this has happened, cos you had to, it, it was not just, well your dad's just gone into St. Thomas's to have a blood test, the seriousness of, of the, his condition required me to say and sometimes they would come in and we may be made that journey at half past 7, 8 and we were still there at midnight which sem,

seemed like forever um and when I asked my son um David about this he said that was the worst, I mean that was just the worst time because you were so helpless, if, if you know you're here in, in your bedroom or in, in, on the sofa, if you're actually in a hospital bed looking like you are getting better because you are having the infection that's raging in you dealt with, but when you're just lying on the trolley um waiting to be taken somewhere then you feel so helpless, totally.

0:19:03

Int. We said earlier that um A&E was at the point the right place to go to although at the same time it was the wrong place to go to, in terms of that helpless feeling what do you think maybe could have been done differently to minimise that feeling for you while you were wait, were waiting?

0:19:27

C1. Well I would like, I would, I suppose to have been introduced or had a form of a companion palliative care person around me that really understood um because uh I, I didn't understand neutropenia until I was a carer, uh I've never, I've never been in that situation with a patient in my 30 years so therefore I totally related to the fact that this was something that you know about but you don't know how you're gonna feel about that when you're so close to it, and uh what, what, we do need to have as, as, as we have progressed within nursing the palliative care, I don't know that that's ever been considered in an A&E um and, and it obviously hadn't been and hasn't been and it's a big gap, a very big gap, and it's not just cancer I mean if, if you've got um a Macmillan nurse but you, you only have a Macmillan nurse in the hospital between 9 and 5 um in, in, in the clinics, so you know could that all be rethought as to um where, where, where people with oncology experience but there will be other conditions that are very obviously terminal too and um will not be at a neutropenic level of understanding but could be a terminal case that's fallen and needs to come in therefore the anxiety of the patient and the relative could still be that this is where I'm going to die and that wasn't my plan, but who asked about the plan, nobody uh and that I think is also uh important. So who would have the time and the skill to realise this patient is having terminal care uh because the condition is lung cancer and it's advanced and we know all of this therefore who was best to talk to um Alan and, and, and Ann uh about the admission and everything. How do they want us to approach it, you know, uh are there any other relatives. Uh I went out to use the mobile phone, nobody asked me anything about that, uh nobody said do you want me to inform any other relatives of that because uh and in a way uh I suppose they, they wouldn't do that cos I was there so maybe that's a question that doesn't get asked, um but it was all very then stressful when the, when the children would come because it was well oh well why, why is he here, oh it's, oh it's an infection is it, oh I see, I thought it was the cancer, and so then you, you, there is no, that, that's for me to educate, I understand that, or for me to get help but when you're in an emergency room well then you are assuming that something's gonna happen in there and uh then of course you've gotta go and wait and, and, and then be clerked in again and then you're asked again, what's the matter, what's wrong, why are you here, why, why have you been admitted today, why do you think you need, why are we, we're now telling somebody on a ward this who then will get a senior person and then they will come and ask us again and I know the importance of the information, the record keeping, but I do question how many times if you're terminal you have to be asked certain questions, and there must be a better format of, of recording, record keeping.

0:23:20



Int. You mention about in A&E having someone ring another member of the family or find out about someone, um if that had happened what, what sort of impact do you think that would have had, how would that have changed things for you, or what would you have even wanted them to ask? That's quite a few questions in one but.

0:23:44

C1. Well I don't, as I was saying it, it was the first time I'd thought of it um so it's not something that I've carried around me thinking nobody asked me this, but in a way you do feel, I felt incredibly lonely and that I had to be strong because, because of Alan and say, oh you know we're, we're waiting but you know what if there was anything really like they were worried about you wouldn't be waiting here you'd have gone somewhere else and using all sorts of methods to keep everybody, to keep him calm which then was keeping me calm um but I had to go out to use the phone to try to get hold of people because I needed, one, I felt responsible that they should know, but two, I needed somebody from home because then what may have been which is when I would just walk back here, and it's just like wow, it's awful. So I think you know do you need anything, is there anything we can do for you um could be asked. I think if you were in a road accident they might ask that question um or if you were in a...

0:24:59

Int. So sorry to pause, it's started crackling again, it's interfering with what you're saying which I don't wanna miss because it's amazing stuff.

(Chitchat)

0:26:39

Int. Okay, I re, really wanna carry on with what you were saying, do you remember what, where you were at, you were just saying about coming back by yourself, okay, so I'll put my hand down when it's on.

0:26:54

C1. You, you feel very lonely because you are frightened anyway, it's not, it's not a this is a heart attack and you know but you've had a cardiac arrest and now you're going to the ward, this has been a trauma to the body in an accident, this is actually uh in, in Alan's case a cancer that he's not going to recover from and that he needs treatment to help him have a sort of quality of his life that's left um with the people he wanted to be with and the only way we can do that is if you can bring this infection down and the temperature down and get him well enough to come back home because the instant he was he was out of bed and back here, um that's all he wanted to do, was go home from the second we took him inside the door. So I knew that to get him home this was the way we'd do it and uh they were doing the best they could but it was no, no one really asked how, how, how are things, uh nobody asked in A&E how are you doing with all of this, uh how are you coping, this is your third time you've come in, how do you feel, is it, is, is there anybody at home for you or, or nothing like that. Now I could be given the impression I don't want those questions asked of me as well because I am super-nurse standing by the trolley um looking like everything's fine and of course in the main it is and, and if they'd have asked all those questions my answer probably would have been no no no, I'm fine, thank you, but on reflection

which is what this, the purpose of the interview is, to reflect on what happened, nobody did ever ever ask and uh and yet when we got to the, to the ward area people were so understanding for me cos I stayed all the time that Alan was in hospital I stayed with him um and so I only come back to get things for me really and then I would go back and, and they gave me a mattress by the, on the floor, uh chairs, no, no problem, I was not a nuisance, I was not made to feel that, everybody understood Alan wanted to go home with Ann as soon as possible. But that never happened in the A&E. I'm sorry, this is really messing up your....

0:29:29

Int. No it's fine, and I've paused it for a bit. Do you want...

(Chitchat)

0:30:21

Int. Um, so when I turn it back on again um probably I will take you back in to A&E if that's okay, and I mean it's amazing what you're saying, it's just inside that I've never seen before so thank you and uh you know just keep talking if you're happy too.

0:30:41

C1. No that's fine, that's fine.

0:30:45

Int. Okay. So you had, how many visits to the A&E did you have in total?

0:31:02

C1. Uh, 5.

0:31:04

Int. Okay.

0:31:04

C1. Yes, and it was uh it became our dread, our fear, the diagnosis obviously was the main cause of anxiety but way up there um was that we'd have to go to A&E and it, we'd do anything and everything and, and we, we didn't you know we didn't have visitors, en, everything we could do uh in our heads that said we must pre, prevent any chance of an infection even though of course we were, we could have had all the visitors in the ward or non and we'd have still have, have had that so we weren't being stupid and mixing with people that had got you know swine flu um we, we were saying um maybe we should just be really really careful and we also had assistance with um some drugs that, that really help to boost your immune system with chemotherapy, they were doing everything and in Alan's head I, I know we were doing everything to avoid going to A&E and, and, and that is absolutely 100 percent the truth, we would go to see Outpatients, we would go for chemotherapy, we would realise the that then um I mean Alan had different forms of radiotherapy and that but the one thing we never wanted to do ever was go through the doors of A&E and of course uh if, if staff see this this is awful and it's not the staff and it's not the building it is just the fact of what that system is in place for people in that, in that situation and

it, it, it has to change, really has to change because people listening to this would be horrified, they would, nobody would want them, us to have gone through that so therefore um it, were, we, we were very aware of that but the reality when we get back here at the, words would be said was let's hope we don't go through all of that again, I can't go again and, and the last time we went I, and I couldn't, I couldn't tell him for ages and I said Alan we've got to uh Alan we've gotta, I've got your jeans here for you, and you've gotta put your sh...shirt on and I've got your bag and we're gonna go downstairs and uh Mark's here, he's got a taxi. Oh no he'd say, no, and that can't be right, uh but that's how it was.

0:33:50

Int. Feeling, being in A&E with him being the strong carer trying to support him um can you just tell me more about that and more about what it was like for you in um on each of the, the different occasions, did it change over the 5 times?

0:34:08

C1. No it, it didn't really because it was always about the waiting, the bloods were done so quickly and of course they came back and confirmed the temperature and confirmed that there'd had to be an admission, the delaying was always with the admission and um at times uh blood pressure uh was deteriorating and we needed to get fluids into him much quicker um but all of that would, that was done was, was really very, managed very well but then there was this, this long gap and the long gap was we, we only saw somebody who came in to take um vital signs, to record the signs and uh nothing else So, so it's really, it, a few hours like that you know it was, someone that's very sick is, is, is hard and for some reason I found it harder than if he'd had a heart attack and was attached to monitors and everything and we're still waiting for a bed, I'd know that he was being looked after by experts for that condition. I felt that there were, were no experts because there are no experts at that A&E or, or in the hospital because actually oncology is all done at Guys so really whose fault is all that, possibly ours because we chose to have, to continue with the treatment where we had the diagnosis cos Alan had, had gained a rapport with the consultant at Charing Cross which is Imperial, so we made it worse I suppose by, by uh not having the, them having access to that, that staff, that consultant, those case notes, but surely a, apart from the IT system which is a separate issue altogether how we share data information but the, the continuity of any care is not there cos, because there wasn't any care because there couldn't be because he, what he needed was uh intravenous antibiotics regularly um regular monitoring of bloods, of temperature um it, ?? a infection control within the side ward and all of that happens after you've left A&E and after you've come through especially a walk-in door um cos I didn't want him to sit there while I was clerking him in, helping to clerk him in with the receptionist, I wanted to take him somewhere else straightaway and I believe there are places that, that have admissions in that way um and I believe there will be changes but I think the changes have also got to be in the reality of the patient and carer experience in this uh is, is quite frightening and, and on talking to a friend who, who actually refused to get out of the ambulance until she knew that she would be going somewhere, that it would not be A&E and that that trolley that she was on was going straight to a ward that knew about her rather than go to A&E and, and that was in the North of England um so it's, it, it, it's an interesting in one way to researchers it's interesting, to carers and to patients it, it, it feels very scary and lonely.

0:38:14

Int. So, I mean those, those feelings of, of fear and loneliness when you're coming in is, if I'm understanding you right is the combination of there not being the skilled

professionals that you need, not being updated, people not being able to access information about your care, um was there anything else uh is there anything that kind of adds onto that in terms of you know you talked about going through those doors and the waiting room and just even the environment itself, the, the physical environment, was there anything with that that kind of compounded things?

0:38:54

C1. Uh well, well your physical environment is, is not right uh and there, there would be either very modern departments uh and A&Es vary around the country as to how they look and how they are and as soon as you get a mixture of patients it looks different a, again um so it's, and it, I mean it's, it's uncontrollable because of, of the way everybody accesses that department but yes there's doubt that I, I would have liked, no I would have liked to have had somewhere that I could like a, a, a day room, somewhere I could sit that I could go and think to make calls, how I said the calls um to the family because in actual fact we are talking about their dad dying and, and I'm doing it on a mobile phone standing outside where I could get a signal and then I can't, they can't call me back because I'm saying no it won't, can't call me back uh text me and then I'll come back outside and, and, and speak to you cos it was difficult what you could say in front of Alan, they were saying do you, could I have a word with my dad and I'm saying yes you could, um that might cheer him up a bit, I'll find a way of doing that, I'll just ask them do, so there was all sorts of communication be, because Alan knew his condition and uh the, the kids did the, and they got to understand how serious uh infection was but we were just there for hours um waiting to, to be taken somewhere else, um and you see that, what, we, we, we always had the very best of um of care from everybody, everybody was always exceptionally apologetic about the wait and we would, kept saying to them don't worry we're, there's no need to, it's okay, we understand uh so uh the alternative to that was to you know say well, well this is wrong that we no, we can't be here or, no, no sane person would do that because nobody would actually want us there if they could have done it better and differently with the system that they have to work to and the system they work to is the same for any um admission really, uh to my knowledge it is anyway, uh and, and so you, you see various people who take a history off you, um you then go through some tests and then you wait for the team that's admitting to come and see you and then um or, or they say to you well they'll see you on the ward when the ward's ready and that can take a very long time. So that's, that, that really, it, without question was, apart from the diagnosis being given and then the prognosis being given, A&E is the worst experience out of everything.

0:42:20

Int. I'm trying to find out as well through your experience um not just you know the, the things that can be improved as negative but what if, if anything was, was there anything positive about not just having to go through A&E itself and so on but was there anything along the way that you took away.

0:42:44

C1. In relation to A&E?

Int. Yeah.

0:42:48

C1. Well, huh, yes, because without them we wouldn't have got, we, we, we knew we had to get to them and we knew that once we'd got there regardless of how busy and difficult it was for, for all sides cos it very obviously was difficult for them you know that you can feel, you can almost feel them thinking oh I can, what can I do here, what is the best thing I can do here for, for these people um so you, you know what's the alternative to that we don't know, the alternative to that if you're in a daytime is you can go to Guys uh to the unit there where they would, would have a room and, and experienced people to talk to um so you, you're, as always you're grateful for the fact that you were getting the appropriate care for the condition in the wrong environment, um, and, and, and that's, so then it doesn't feel as appropriate because you're not in the right environment to receive it, so your, your expectations are changing all the time and then your expectations you realise you're actually in A&E and there's nothing else anybody can do, and you're not, you're not taken straight to a, a specialist nurse, medic who talks you through everything, gets you set up and talks to relatives about what, what's taking place, you, you are receiving the only care they can give you in the best way that they can in the wrong environment.

0:44:40

Int. And just um just the layout it's wrong because.

0:44:47

C1. Well I think the staff there are put in a difficult situation because we're constantly saying what is an accident, what is an emergency, well in a way neutropenia is, is a medical emergency, there's no doubt about that um but it, it, it still is being delivered with a team of people that are working full out in every cu, cubicle with people waiting to come into cubicles with uh all sorts going on uh even we experienced shift changeovers and everything and it, it's just for them uh I'm sure they are wanting it to be different, they're wanting to use, like we all do, we want to, we want to practise to our knowledge level and we want to practise with the patient in, in partnership with them in the best way we can and you can't, you can't do that with, you, all A&E staff in all A&E circumstances if you are requiring palliative care in particular and, and yes the palliative care is also urgent care and, and so that's almost a contradiction in, in terms because you're requiring palliative care in an emergency room.

0:46:20

Int. Yeah, I think starting to come to the end, but I wanted to know is there anything that really stuck out to you while in any of those 5 instances of being in A&E, what, did anything sort of remain with you still to this time of any type?

0:46:43

C1. Uh yes the, the, that, of that I'm very positive um that when doctors would take a history from Alan he would, it was obvious that they were so concerned that somebody should be a fit older person, very fit, uh very able um saying his life history and had terminal lung cancer and they felt, they, you could see they felt useless and, and we're trying hard to be positive with him when they were going to the next cubicle which was a totally different situation and, so they were having to switch their emotions um all over the place with 2 people that were just holding on to theirs but who really just wanted to cry.

0:47:41

Int. Do you want?

(Pause/chitchat)

0:48:24

Int. Are you alright to continue?

C1. Yeah, yeah yeah, alright.

0:48:26

Int. Great, I mean we, we're nearly done anyway.

C1. Okay.

0:48:29

Int. Unless there's more that, I mean in terms of...

0:48:31

C1. No I, I know I've said what I want to say, I think I've repeated it once or twice, so uh, uh it, it, I think the phrase I want is it's, it, you want urgent palliative care.

0:48:43

Int. I'm gonna start recording again, sorry.

0:48:50

C1. It, it, it's, it's a, a strange statement to say you want urgent palliative care and was it, was all of our conversations delivered with kindness, yes, but it was a very long drawn out procedure and it was repetitive and it didn't seem to be asking what we wanted to ask and what I wanted to ask was could we get him fit enough to come home as quick as possible please because we don't want to be in hospital, we want to have palliative care at home but we have to come here because of the situation and the immune system and everything and could we do this, I wanted to scream, could we do this a different way please.

0:49:47

Int. Is there anything you want to add or say before, before we ?? anything more?

0:49:57

C1. Well I, I certainly have the opportunity to thank people for all the care that they gave cos they did uh and to me um but other, I will repeat myself, palliative care can, how can palliative care be given in the emergency room and how aware are the people that work in that room of the need for it to be palliative care because it's all about saving life and of course that's what I wanted to happen then because we were, he didn't want to die in A&E and the only way that we could achieve what we wanted was to come through A&E, and so I think so much more work uh where, where readily agreed to do this anything that would help all of us understand that differently and improve that has to be the right way forward.

0:50:56

Int. Um.

C1. Okay?

Int. Um. Well now I'm gonna cry. Thank you.

C1. It, it's tough, it's great what you're doing Becky, that's why I love you, well it's not the only reason, it's only because you're naughty...

(Chitchat)

**END OF TRANSCRIPTION**

SOUND TRANSCRIPTION FOR: Rebecca Blackwell

INTERVIEW WITH: C1

**FILE NUMBER:** 2 of 2

**TRANSCRIPTION DATE:** 15.09.14

**REQUESTED BY:** REBECCA BLACKWELL

0:00:09

Int. So just as we were finishing you'd started to say.

0:00:15

C1. You, you see what do I mean by palliative care, um do I mean I want somebody to sit next to Alan, hold his hand and ask him has he thought about his death and all of those things attached to such difficult conversations, uh no, I wanted people to realise, the staff to realise that we did have a plan, that Alan and I had a plan, we hadn't discussed it with anybody and we only discussed it when it comes to the um discharge from hospital because Alan starts saying straightaway can I, well can I go home today after I had the last antibiotic, well that won't be till 9 o'clock at night Alan, I don't care, because Ann's here and uh Ann will look after me but I want to go home, so it was to the forefront of his mind he needed to go home, therefore who knew that when we were in A&E because nobody had asked us any of those questions and uh that therefore to us the urgency was get him in quick, fix him quick and let's get back home so we can continue with the care we wanted and that, and of course those, none of those question uh how would anybody know that and because we're, we're not asked and it's not suitable for me to start talking in that way because

we're still in a sit, in, in, mentally we're still in an, an emergency um feeling so we're not in a, I'm not in a palliative care I am in, my husband is really sick, do something now, so it's an emergency frame of mind I'm in requiring a palliative care atmosphere I suppose and I don't know whether that's, I don't know whether that's possible but I don't think it's possible for me to feel better or patients or any other carers to feel better if we don't seriously look at this to say there is a way that surely we could start to meet some of these really serious emotions cos fear is, fear is quite a strong emotion and uh I would let him down if I didn't get him home, so there, therefore the emergency treatment was imperative as if it was chest pain um but this emergency treatment was so as he could have his palliative care. I don't know what to say anymore.

0:03:04

(Chitchat)

**END OF TRANSCRIPTION**



## Appendix 23: Validation Survey

### Improving Experiences of Palliative Care for Older People, their carers and staff in the Emergency Department

**PLEASE ONLY RANK THE TOP THREE** ways in which the provision of care for older patients with palliative care needs and their carers should be improved in the Emergency Department

**1 = most importance,**

**2 = 2<sup>nd</sup> most important**

**3 = 3<sup>rd</sup> most important).**

IMPROVEMENT PRIORITIES	RANK
Systems and Process To do with the overall health system and A&E specifically e.g. waiting times, environment	
Communication and Information The encounters you had with staff, and how information was shared between services, staff and with you.	
Acknowledgement and Validation How well your own experience was understood and recognised by staff. If you were supported or unsupported. Roles and impact on patients/carers.	
Recommendations Suggestions put forward for improving the delivery of palliative care in A&E.	
Changing Culture Factors relating to an ageing population with different care needs who now need to use the A&E. Other cultural changes.	

In your interview you will see segments in different colours. These indicate the following five issues and the quotes from your interview that may be used in the final film. Please let the researcher know if you do not want any of these quotes included.

#### **Five Broad Themes:**

- 1. Systems and Process**
- 2. Communication and Information**
- 3. Acknowledgement and Validation**
- 4. Recommendations**
- 5. Changing Culture**

## Appendix 24: Patient/carer information sheet

### INFORMATION SHEET FOR PARTICIPANTS

*REC Reference Number: 14/LO/0136*

#### **Improving the experiences of palliative care in the Emergency Department for older people, their carers and staff using Experience-based Co-design**

We would like to invite you to participate in this postgraduate research project, funded by a King's College London Health Schools Postgraduate Studentship in collaboration with Guy's and St Thomas' NHS Foundation Trust. **You should only participate if you want to; choosing not to take part will not disadvantage you in any way.** Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

**NB: palliative care can be given to someone with an incurable, often long-term, life-limiting condition, for example, chronic obstructive pulmonary disease (COPD), heart failure, cancer or neurological disease such as Parkinson's. Palliative care looks to offer total support (medical, social, psychological and spiritual) to patients and their families.**

#### **What is the purpose of this research?**

The purpose of this research is to explore and improve experiences of palliative care delivery for older people with palliative care needs, their carers (family members) and staff in Accident & Emergency (A&E) departments. The study aims to understand the needs of patients, carers and staff to identify where there may be difficulties. You are invited to share your experiences and then work alongside other patients, carers and emergency staff to use your shared experiences to redesign the service and improve palliative care delivery at St Thomas' Hospital A&E.

#### **Why is this research being done?**

This project comes from evidence that the use of the A&E by older people with palliative care needs can often be a distressing experience for all involved. As the A&E was not originally designed to meet the type of needs that these patients have, it can be very difficult for staff to provide the best care for them.

This research aims to explore the experiences of the patients, carers and staff in order to identify ways to improve the service and experience for all involved.

### **Why have I been chosen (inclusion criteria)?**

This project focuses on the experience of A&E staff, older people with palliative care needs and their carers who have used St Thomas' Hospital Accident and Emergency Department. As a patient at this hospital, aged 65 or older with a long-term condition or a carer (family member or informal carer) of a person aged 65 or older who has used the A&E you are ideally placed to tell us how to improve the patient and carer experience of this service.

### **What will happen if I agree to take part?**

You are invited to take part in the study which is being conducted in three phases over the course of one year (see below). You have the option to take part in all three phases, or in phases 1 and 2, or solely in phase 3.

#### **Phase 1: An interview about your experience by the lead researcher, Rebecca Blackwell**

During the interviews you will be asked to tell your story of being a patient or carer in A&E. With your permission this interview will be audio recorded and filmed. We ask permission to film the interviews as this is a powerful method of identifying issues and sharing experiences. Recordings of interviews will be transcribed and then the audio recording will be deleted.

#### **Phase 2: Viewing your film**

The filmed interview will be returned to you so you can view it and decide whether to agree to parts of the film being shared with other patients and staff. You will be given a release and consent form to sign specifically relating to the use of this data.

You will also be asked to fill in a short form based on the information given from the patient and carer interviews, asking you to identify the main areas you feel are a priority for improving palliative care in the A&E.

#### **Phase 3: Attending a co-design event**

In Phase 3 a workshop, known as co-design event, will be held. Patients, carers, staff and any other care groups or services that link with A&E will be invited to attend. The aim of this session is to work together in groups to design better patient and staff experiences. A short DVD made of a collection of key moments from different patients and carers, as agreed upon in Phase 2, along with information collected from staff interviews will be used to help with this process. Notes will be made documenting the event, and photographs will be taken to be used in dissemination activities such as presentations, as well as the final thesis for this study. If you do not wish to be in photographs, you will be given a

red sticker to put on your name badge. If you are willing to be in photographs you will be given a blue sticker.



### **What are the possible disadvantages of taking part?**

The interview will take about 60 minutes and will be held in a venue that is convenient for you. You will be asked to share your story of being in the A&E. The questions should not be upsetting for you but if you are free to stop the interview at point if you wish to. With your permission, your GP will be notified about your participation in the study and will be available if you need to discuss any issues raised in the interview, or be referred for additional support to your hospital consultant.

### **Possible benefits**

The findings are expected improve services in the A&E Department at St Thomas' Hospital for patients and their families and/or carers. Although this may not benefit you personally, the information you give may help influence and shape services in the future.

### **What information will be held about me?**

We will follow ethical and legal practice and all information about you will be handled in confidence as per the UK Data Protection Act 1998. The data collected for the study will be analysed to learn more about the experiences of patients and carers with palliative care needs in A&E.

To ensure your confidentiality is maintained only the research team will have access to identifiable information that you provide. The audio recorded interviews will be coded using numbers and will not show your name before they are sent to an external service for transcription. The audio tapes of the interview will be destroyed once they have been transcribed and analysed. They will be kept in a locked file in a locked room at King's College London.

A short DVD will be made from the filmed interviews. This will include short segments from the patient and carer interviews. No information on your condition, name or location will be on the DVD. The DVD will be kept – with your permission – to be used as an education tool for healthcare professionals working in A&E.

To protect your confidentiality, your name, condition and personal details will not be shared in the thesis of this project and any subsequent publications, and you will not be identifiable from any quotes used from your interview.

The Chief Investigator, Rebecca Blackwell, will be responsible for security and access to the data. At the end of the study, any information you provided will be secured for seven years in keeping with standard research practice, before being destroyed as confidential waste

### **What will happen to the results of the research study?**

The results will be shared with healthcare staff as part of service improvement work at St Thomas' A&E. The study will be written up in the PhD thesis of this study, published in professional journals and presented at healthcare conferences. The results may be shared online as part of on-going service improvement work and may also include international service improvement work.

### **FAQs**

#### **5) Do I have to take part?**

No. It is up to you to decide whether to take part or not. If you decide to take part you are free to withdraw from the study at any time and without giving a reason.

#### **6) If I change my mind about being the study can I withdraw my information and data?**

You can withdraw your data up to the end of Phase 2 when the DVD will be made (July 2014). However you can withdraw your active participation in the study at any stage without giving a reason.

#### **7) Will I be contacted about future studies?**

If you agree to take part you will be asked whether you are happy to be contacted about participation in future studies. You are free to decline. Your participation in this study will not be affected should you choose not to be re-contacted.

#### **8) What will happen next?**

If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. The researcher will then contact you to arrange a time and place convenient to you, to carry out the interview.

If you have any questions or require more information about this study, please contact the researcher using the following contact details:

Principle Investigator: Rebecca Blackwell. [rebecca.blackwell@kcl.ac.uk](mailto:rebecca.blackwell@kcl.ac.uk)

### Complaints or Concerns

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (Rebecca Blackwell [rebecca.blackwell@kcl.ac.uk](mailto:rebecca.blackwell@kcl.ac.uk)). If you remain unhappy and wish to complain formally, you can:

- Telephone the complaints department on 020 7188 3514
- E-mail your complaint to [Complaints2@gstt.nhs.uk](mailto:Complaints2@gstt.nhs.uk)
- Write to the Chief Executive, Ron Kerr at the address below
- Write to the complaints department at the address below

Guy's and St Thomas' NHS Foundation Trust  
Guy's Hospital  
Great Maze Pond  
London SE1 9RT

## Appendix 25: Co-design event extract from information sheet

### INFORMATION SHEET FOR PARTICIPANTS

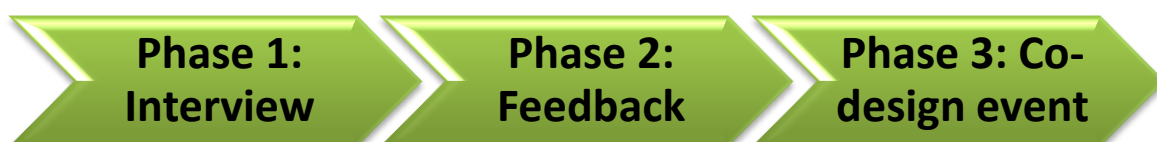
*REC Reference Number: 14/LO/0136*

Improving the experiences of palliative care in the Emergency Department for older people, their carers and staff using Experience-based Co-design

#### **Extract from Information sheet:**

##### Phase 3: Attending a co-design event

In Phase 3 a workshop, known as co-design event, will be held. Patients, carers, staff and any other care groups or services that link with A&E will be invited to attend. The aim of this session is to work together in groups to design better patient and staff experiences. A short DVD made of a collection of key moments from different patients and carers, as agreed upon in Phase 2, along with information collected from staff interviews will be used to help with this process. Notes will be made documenting the event, and photographs will be taken to be used in dissemination activities such as presentations, as well as the final thesis for this study. If you do not wish to be in photographs, you will be given a red sticker to put on your name badge. If you are willing to be in photographs you will be given a blue sticker.



## Appendix 26: Co-design event invitation

**Invitation to co-design event for the study: *Improving experiences of palliative care for older people, their carers and staff in the emergency department using experience-based co-design.***

**Date:**

**Wednesday 19<sup>th</sup> November 2014**

**Time:**

**Refreshments from 10:15am**

**Start at 10:30am**

**Finish 12:45pm**

**Location:**

**Seminar Room 3, Education Centre, 75-79 York Road, London SE1 7NJ** (Please see attached map)

Refreshments will be provided and travel costs will be reimbursed to the sum of £10.

For further information please contact Rebecca Blackwell on: 07753681390,

[Rebecca.blackwell@kcl.ac.uk](mailto:Rebecca.blackwell@kcl.ac.uk)

Please see the attached information sheet for further details and directions

**Travel Information:**

The nearest **TUBE** stations are:

- Westminster - District, Circle and Jubilee lines (10 minutes' walk)
- Waterloo - Bakerloo, Jubilee and Northern lines (five minutes' walk)
- Lambeth North - Bakerloo line (10 minutes' walk).

The nearest **TRAIN** stations are:

- Waterloo (five minutes' walk)
- Waterloo East (10 minutes' walk)
- Charing Cross (15 minutes' walk).

For more information, please call National Rail Enquiries on 08457 484 950 or visit [National Rail website](#).

The following **BUS** routes stop near the education centre:

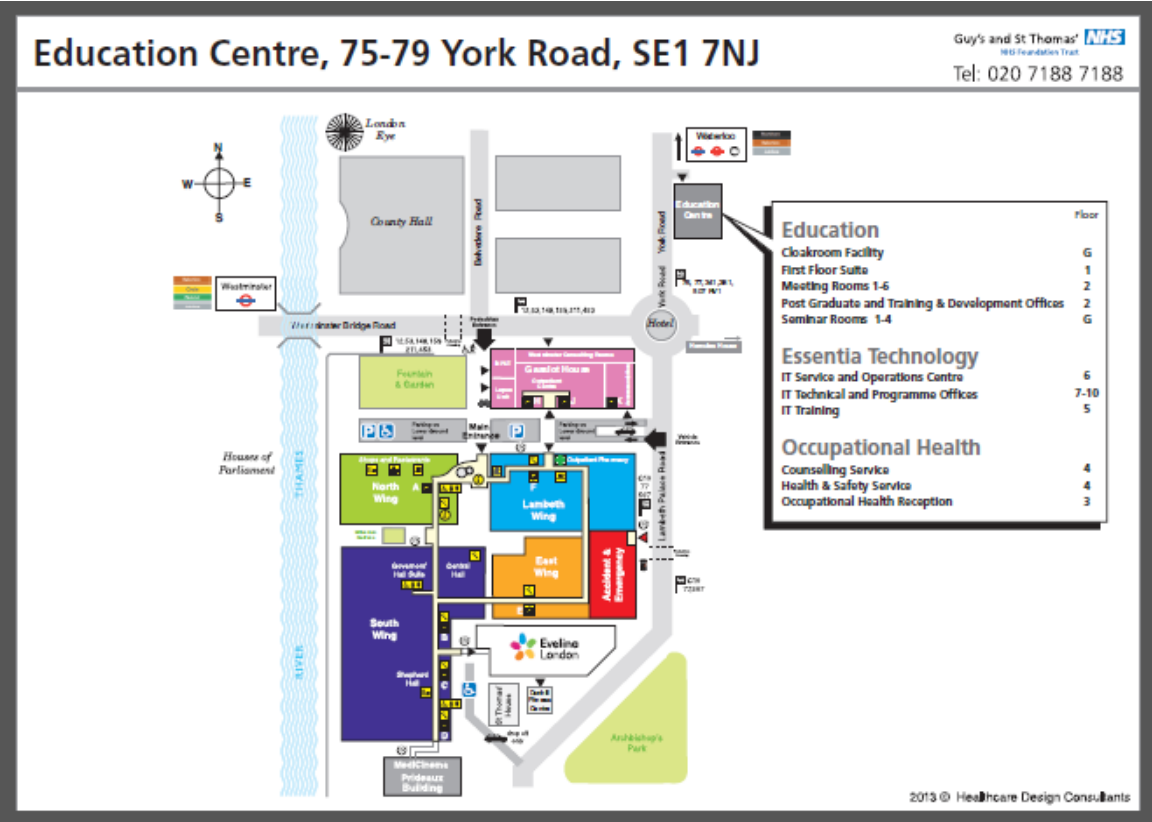
- 12, 53, 148, 159, 211, 453, C10 - stop at Westminster Bridge Road
- 76, 341, 381, RV1 - stop at York Road.

For further information about buses and tubes, please call Transport for London on 020 7222 1234 (24 hours) or visit the [Transport for London journey planner website](#).

There is no parking at the Education Centre. Please use public transport whenever possible.



Appendix 27: Map of location for co-design event



## **Appendix 28: Staff information sheet**

### **INFORMATION SHEET FOR PARTICIPANTS: STAFF**

*REC Reference Number: 14/LO/0136*

### **YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET**

#### **Improving the experiences of palliative care in the Emergency Department for older people, their carers and staff using Experience-based Co-design**

We would like to invite you to participate in this postgraduate research project, funded by a King's College London Health Schools Postgraduate Studentship in collaboration with Guy's and St Thomas' NHS Foundation Trust. **You should only participate if you want to; choosing not to take part will not disadvantage you in any way.** Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

#### **What is the purpose of this research?**

The purpose of this research is to explore and improve experiences of palliative care delivery for older people with palliative care needs, their carers (family members) and staff in Accident & Emergency (A&E) departments. The study aims to understand the needs of patients, carers and staff to identify where there may be difficulties. Based on information that has been shared by patients, carers and emergency staff, you are invited to attend a co-design event to use your shared experiences to redesign the service and improve palliative care delivery at St Thomas' Hospital A&E.

#### **Why is this research being done?**

This project comes from evidence that the use of the A&E by older people with palliative care needs can often be a distressing experience for all involved. As the A&E was not originally designed to meet the type of needs that these patients have, it can be very difficult for staff to provide the best care for them.

This research aims to explore the experiences of the patients, carers and staff in order to identify ways to improve the service and experience for all involved.

#### **Why have I been chosen (inclusion criteria)?**

This project focuses on the experience of A&E staff, older people with palliative care needs and their carers who have used St Thomas' Hospital Accident and Emergency Department. As a member of staff affiliated with this department you are ideally placed to join the co-design event to agree service improvement priorities for staff, patients and carer.

### **What will happen if I agree to take part?**

You will attend a workshop, known as co-design event. Patients, carers, staff and any other care groups or services that link with A&E will be invited to attend. The aim of this session is to work together in groups to design better patient and staff experiences. A short DVD made of a collection of key moments from different patients and carers, along with information collected from staff interviews will be used to help with this process. The event will be documented in note form for analysis, and photographs will be taken to be used in dissemination activities such as presentations, as well as the final thesis for this project. You will be given the choice of a red or blue sticker to put on your name badge to indicate your willingness to be photographed. Red indicates refusal and blue indicates permission.

### **What are the possible disadvantages of taking part?**

The topic may bring distressing experiences to mind. The Clinical Lead and Practice Development Nurse (Dr Katherine Henderson & Nikki Helder) will be available and able to offer support should you require it.

### **Possible benefits**

The findings are expected improve services in the A&E Department at St Thomas' Hospital for staff, patients and their families and/or carers. Although this may not benefit you personally, the information you give may help influence and shape services in the future.

### **What information will be held about me?**

We will follow ethical and legal practice and all information about you will be handled in confidence as per the UK Data Protection Act 1998. The data collected for the study will be analysed to learn more about the experiences of patients and carers with palliative care needs in A&E, and the staff caring for them.

No identifiable data will be held about you, although you will be asked document your job title on the day of the co-design event. Field notes will be collected during the event as a record of the service improvement priorities and strategies that emerge. All data collected will be kept in a locked file in a locked room at King's College London.

To protect your confidentiality, any personal information you choose to share will not be shared in the thesis of this project or any subsequent publications, and you will not be identifiable from any quotes used from the co-design event.

The Chief Investigator, Rebecca Blackwell, will be responsible for security and access to the data. At the end of the study, any information you provided will be secured for seven years in keeping with standard research practice, before being destroyed as confidential waste

### **What will happen to the results of the research study?**

The findings will be used by St Thomas' Hospital as part of their developmental work within the A&E department. The study will be written up in the PhD thesis of this study, published in professional journals and presented at healthcare conferences. The results may be shared online as part of on-going service improvement work and may also include international service improvement work.

### **FAQs**

#### **9) Do I have to take part?**

No. It is up to you to decide whether to take part or not. If you decide to take part you are free to withdraw from the study at any time and without giving a reason.

#### **10) If I change my mind about being the study can I withdraw my data?**

You can withdraw at any stage without giving a reason. As you will not be able to be identified from any data collected from the co-design event you will not be able to withdraw any input you have made.

#### **11) Will I be contacted about future studies?**

If you agree to take part you will be asked whether you are happy to be contacted about participation in future studies. You are free to decline. Your participation in this study will not be affected should you choose not to be re-contacted.

#### **12) What will happen next?**

If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. The researcher will then contact you to inform you of the date, time and location of the co-design event.

If you have any questions or require more information about this study, please contact the researcher using the following contact details:

Principle Investigator: Rebecca Blackwell. [rebecca.blackwell@kcl.ac.uk](mailto:rebecca.blackwell@kcl.ac.uk)

### Complaints or Concerns

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (Rebecca Blackwell [rebecca.blackwell@kcl.ac.uk](mailto:rebecca.blackwell@kcl.ac.uk)). If you remain unhappy and wish to complain formally, you can:

- Telephone the complaints department on 020 7188 3514
- E-mail your complaint to [Complaints2@gstt.nhs.uk](mailto:Complaints2@gstt.nhs.uk)
- Write to the Chief Executive, Ron Kerr at the address below
- Write to the complaints department at the address below

Guy's and St Thomas' NHS Foundation Trust  
Guy's Hospital  
Great Maze Pond  
London SE1 9RT

## Appendix 29: Co-design event consent form



King's College London  
James Clerk Maxwell Building  
57 Waterloo Road  
London SE1 8WA

Centre Number:

Study Number: 14/LO/0136

Identification Number for this trial:

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### CONSENT FORM – Co-design Event

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Title of Project: **Improving the experiences of palliative care in the Emergency Department for older people, their carers and staff using Experience-based Co-design**

Name of Researcher: **Rebecca Blackwell**

Please initial all boxes

10. I confirm that I have read and understand the information sheet dated 02/01/2014 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
11. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
12. I understand that if I decide at any time during the research that I no longer wish to participate in this project, I can notify the researchers involved and withdraw from it immediately without giving any reason. ☐
13. I agree that the research team may use my data for future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. (In such cases, as with this project, only filmed data would be identifiable in any report). ☐
14. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications ☐

15. I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 1998.

☐

16. I agree to participate in Phase 3 (Co-design workshops) and will wear a red or blue sticker on my name badge to indicate my willingness to be photographed.

☐

17. I would like a copy of any publications about this work.

☐

18. I am happy to be contacted by the researchers regarding future work on this topic.

☐

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Name of Participant

---

Date

---

Signature

---

Name of Person

---

Date

---

Signature

taking consent.

## Appendix 30: Patient/carer film evaluation form

### Evaluation Form: Patients and carers

#### Improving experiences of palliative care in the Accident and Emergency Department for older patients, their carers and staff using Experience-based Co-design

Your reactions to watching the film

Does it represent your experience as a patient or carer?

Is there anything you would like to add to the film or the event today?



## **Appendix 31: Staff film evaluation form**

### **Evaluation Form: Patients and carers**

#### **Improving experiences of palliative care in the Accident and Emergency Department for older patients, their carers and staff using Experience-based Co-design**

Your reactions to watching the film

Does it represent your experience as a patient or carer?

Is there anything you would like to add to the film or the event today?

## Appendix 32: Overall event evaluation form

### Palliative Care in A&E: Co-design Event Evaluation Form

Please give us your overall impressions and feelings about:

1. Seeing the patient/carer experience film and the staff presentation – did you think it was a good representation of what it is like to be a patient, carer or staff member at Guy's and St Thomas' NHS Foundation Trust, Accident and Emergency Department? (Please circle/underline and add any comments)

*Excellent*                      *Good*                      *Average*                      *Poor*                      *Very poor*

Please comment:

2. Your experience of watching the film

*Excellent*                      *Good*                      *Average*                      *Poor*                      *Very poor*

Please comment

3. Meeting other patients, carers and staff and talking about your experiences

*Excellent*                      *Good*                      *Average*                      *Poor*                      *Very poor*

Please comment

4. The discussion groups as a way to reflect on your experiences and identify priorities for improving the service

*Excellent*                      *Good*                      *Average*                      *Poor*                      *Very poor*

Please comment

5. Do you feel the priorities agreed at the end of the day reflect your own experiences of what needs to be improved? Please comment

6. What could be improved if this event were to be run again?

7. Do you have any other comments you would like to add?

Organisation of the event (please tick	Excellent	Good	Average	Poor	Very poor
Pre event information					
Directions to the venue					
Accessibility of venue					
Catering					

*Many thanks for all of your comments and thoughts.*

### Appendix 33: Proposed Publications Outline

Publication	Working Title	Outline	Journal	Impact Factor	Timeline
Paper 1	Critically appraising Experience-based Co-design as a methodology for understanding complex threads: improving palliative care for older people in the ED.	<b>Methodology paper</b> reporting on the development of EBCD in my study. The paper will reflect on the use of the approach in brining together three complex different but overlapping threads (palliative care, older people, the ED). The development of the conceptual framework is presented as a way of understanding and breaking down experience to identify the trigger points. In demonstrating how this was done, the paper will explore the type of involvement from the participant and how it was possible to have varying degrees of involvement from different people but still maintain its shape as an EBCD project. This paper responds to the Donetto et al (2014) report which asks design practitioners to report on the nature of critical thinking needed to increase the impact of co-design approaches in the healthcare setting. The flexibility of approach which gave a structure but allowed people to come in and out i.e. the patients and staff, found that more changes happened intuitively in practice than if the structure had insisted on the same population throughout. The paper provides the foundation for the three 'findings' papers.	The Journal of Applied Behavioural Science	0.914	This is the first paper. I will begin working on it as soon as the changes and corrections are done to the thesis. I hope to have a full draft before I move in September and to submit by the end of the year. This is being given longer as I will be moving to New York in this time and starting my new workload and I am uncertain of the timing of all of the things right now.

Publication	Working Title	Outline	Journal	Impact Factor	Timeline
Paper 2	Developing design principles for improving palliative care in the ED: exploring the work of the GEDI WISE team in the US for application in the UK	<p><b><u>Organisational development paper.</u></b> This paper presents the findings and process of analysis undertaken at Mount Sinai and the design principles developed. This paper will simplify the analysis process (if possible), demonstrating the frames that the data was taken through to its final iteration. The full design principles and final iteration will be included. Their use at GSTT is referenced with an acknowledgment that although the design principles appear to be useful, further research and exploration are required to determine if they serve as an effective tool in healthcare design work.</p> <p>.This publication will present a brief outline of the purpose of the Mount Sinai visit. It will draw on the work of Plsek to show how his strategies for translating instinctive staff knowledge into practical applicable suggestions was applied in this context.</p>	<p>The Journal of Applied behavioural Science</p> <p>Evaluation</p>	<p>0.914</p> <p>1.906</p>	<p>This publication is the second paper as the outcome of the NY work has been waiting to be published since 2013. In addition there is interest in this work and I was advised in the viva to publish this quickly along with the methodology paper. I will begin putting this paper together in October/November 2015 when I am in New York as I will then have direct access to the GEDI WISE team again to get quick feedback. I would hope to have a full draft ready by February 2016.</p>

Publication	Working Title	Outline	Journal	Impact Factor	Timeline
Paper 3	Improving palliative care for older people, their carers and staff in the ED: staff perceptions, understanding and improvement priorities.	<b>Findings paper 1.</b> This is the first findings paper which reports on the study and will be written as a traditional data findings paper reporting on qualitative research (background, collection, analysis, validation, findings, discussion, conclusion). The data collection, analysis, validation and selection of <b>staff</b> improvement priorities are shared as they pertain to the wider literature on the topic and the themes will be analysed more broadly. This paper builds on the work of Bailey and Grudzen as well as others who have published in this area, giving more insight into the palliative care experiences and concerns of ED staff. The problems and challenges highlighted by staff will be discussed, along with the potential solutions. This paper is presented as an EBCD study but refers to the data rather than the conduct of the study, referring to publication 1 for this depth of discussion and reflection on methodology.	Annals of Emergency Medicine  Academic Emergency Medicine	4.333  2.198	I intent to work on paper 3-5 concurrently through the first six months of 2016. This has generally been a way I find I am able to be productive and so I aim to have a full draft completed by July 2016

Publication	Working Title	Outline	Journal	Impact Factor	Timeline
Paper 4	Improving palliative care for older people and their carers and staff in the ED: patient and carer perceptions, understanding and improvement priorities.	<b>Findings paper 2.</b> This paper presents the data collection, analysis, validation and selection of improvement priorities from the <b>patients and carers</b> using the same structure as publication 2. This paper is designed to join the limited existing evidence on the experiences of palliative care in the ED for older people and their carers. The focus of this paper is on a greater exploration of the themes identified from the initial data analysis and the patient and carer selection of improvement priorities are highlighted with quotes to demonstrate the expectations and understanding of the ED experience, and to connect to the wider literature, filling a gap looking at what they actually want in the ED. The limitations and small patient sample is acknowledged with a call for further research to see if these findings are commonly shared.	Palliative Medicine  Journal of Palliative Medicine	2.845  2.063	I intent to work on paper 3-5 concurrently through the first six months of 2016. This has generally been a way I find I am able to be productive and so I aim to have a full draft completed by July 2016

Publication	Working Title	Outline	Journal	Impact Factor	Timeline
Paper 5	Improving palliative care for older people, their carers and staff in the ED: co-designing the changes	<p><b><u>Findings paper 3.</u></b> The third findings paper presents <b><u>the co-design event.</u></b> The purpose of this paper is to present the conclusion of the study, the collaborative working, and the challenges and potential to initiative co-design between three vulnerable populations (palliative older patients, bereaved/still caring carers/ED staff). This paper refers back to the findings of papers 3 and 4, showing the overlap and relationship between the challenges facing the ED staff, the patients and the carers. The paper refers to the methodology of EBDC and how it was applied at this stage. The impact of the film is made clear, as is the creation of a second film. The paper discusses the weakness of the staff presentation as a means of sharing the improvement priorities and experience compared to the patient film and suggests that having the staff story captured in some way electronically/visually/audio may be beneficial to other studies.</p> <p>.This publication will provide a brief background into the project, and an overview of EBCD before going on present the conduct of the event and the outcomes. A discussion will reflect on the challenges of getting people to the event, of not having prior group meetings and how these challenges were addressed and learned from. The paper will conclude with a summary of the outcomes as they could apply to other EDs.</p>	<p>Qualitative Health Research</p> <p>BMC Palliative Care</p>	<p>1.441</p> <p>1.78</p>	I intent to work on paper 3-5 concurrently through the first six months of 2016. This has generally been a way I find I am able to be productive and so I aim to have a full draft completed by July 2016



Publication	Working Title	Outline	Journal	Impact Factor	Timeline
Paper 6	Complex roles: the ethics of becoming a nurse researcher	<b>Discussion paper</b> exploring the dual role of nurse and researcher. The paper discusses some of the ethical issues I encountered and how I learned to manage my new role, particularly when I was often still seen as a healthcare professional rather than a researcher. This paper builds on the work of Bailey/Cribb/others as it applied to this study. The paper will end with conclusions for consideration in future research with older, palliative care patients and bereaved carers and practical suggestions for managing changing roles.	International Journal of Nursing Studies	2.901	This paper requires further reflection and exploration into any debates about roles of nurses and managing complex boundaries. It will be the final paper of the six, to be written on completion of the others, but developed alongside them as my reflections develop.

## Appendix 34: Development Log

### Events Attended

Type	Title	Organisation	Date
Conference Attended	Lost In Translation. End of Life Care	International Journal of Palliative Nursing and the British Journal of Hospital Medicine	03-Oct-13
Conference Attended	National End of Life Care Programme Conference	National End of Life Care Programme	13-Sep-12
Conference Attended	Tackling Long Term Conditions	Health and Wellbeing Event	30-May-12
Conference Attended	PhD Student Conference	Manchester Institute for Collaborative Research on Ageing	30-Mar-12
Conference Attended	Transforming end of life care in acute hospitals	National End of Life Care Programme	29-Feb-12
Type	Title	Organisation	Date
Seminar Attended	Palliative and end of life care: next steps...	Westminster Health Forum	04-Feb-14
Seminar Attended	Service User and Carer Experience Network - launch event. South East London	Health Innovation Network	04-Nov-13
Seminar Attended	Annual Lecture	Cicely Saunders Institute	09-May-13
Seminar Attended	Who Cares? (Carers of end of life patients)	National Council for Palliative Care	06-Nov-12
Seminar Attended	Experience-Based Co-Design Training & Sharing Day	King's College London	13-Jul-12
Seminar Attended	End of Life Care Masterclass	M&K Update	17-Jun-11

### Dissemination Opportunities

Type	Title	Organisation	Date
Conference Presentation	Transforming the patient and staff experience	The King's Fund	05-Nov-14
Conference Presentation	Palliative Care for older people in the ED	End of Life Care Facilitators Group	16-Oct-14
Conference Presentation	End of Life Care in A&E	NHS Improving Quality	24-Mar-14
Conference Presentation	Masterclass: 'Grey Expectations'	Florence Nightingale Foundation	27-Feb-14
Conference Presentation	Compassionate death in hospital	National Council for Palliative Care	10-Feb-14
Conference Presentation	Caring for older people conference	M&K Update	16-Apr-13
Type	Title	Organisation	Date
Poster Presentation	Annual Conference	College of Emergency Medicine	24-Sep-13
Poster Presentation	Postgraduate Research Symposium	King's College London	12-Jun-12
Type	Title	Organisation	Date
Seminar Presentation	PhD overview	Research Team from the Karolinska Institutet in Sweden	02-Feb-15
Seminar Presentation	My PhD	BHR Hospitals NHS Trust Palliative Care Team	17-Jun-14
Seminar Presentation	Palliative Care in the Emergency Department: PhD	King's College London	22-Nov-13
Seminar Presentation	Development of Transferable Design Principles	King's College London	21-Nov-13
Type	Title	Organisation	Date
Teaching Presentation	A&E Course (MSc)	King's College London	12-Feb-15
Teaching Presentation	A&E Course (MSc)	King's College London	11-Dec-14
Teaching Presentation	Palliative care in the ED	St Thomas' ED	25-Sep-14
Teaching Presentation	Advancing Nursing Practice through Research (MSc)	King's College London and St Christopher's Hospice	20-Mar-14

### Affiliations and Networks

Organisation	Role	Event	Date
Florence Nightingale Foundation	Scholar	Trustees, Chairs and Scholars Dinner	22-Jan-13
	Steering Group Member	FNF Alumni Association Steering Group	On-going
	Scholar	FNF Executive Strategy Away Day	03-Feb-15
Organisation	Role	Event	Date
King's College London	Steering Group Member	Athena Swan Steering Group for Silver Award (Successful bid)	On-going
Organisation	Role	Event	Date
Marie Curie Cancer Care	Affiliate/Consultant	On-going meetings with Head of Nursing	On-going
	Supporter	Launch of The Great Daffodil Appeal, House of Commons	18-Mar-15
Organisation	Role	Event	Date
Guy's and St Thomas' NHS Foundation Trust	Honorary Clinical Observer	Teaching Research	2012-2015
	Steering Group Member	Palliative Care Team: inpatient palliative care unit planning group	06-Jul-05